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**AN EVALUATION OF A NEW
DOMICILIARY PHYSIOTHERAPY
SERVICE**

PAMELA DAWSON

**A THESIS SUBMITTED IN PARTIAL
FULFILMENT OF THE
REQUIREMENTS OF THE
UNIVERSITY OF NORTHUMBRIA AT
NEWCASTLE FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY**

SEPTEMBER 2000

ACKNOWLEDGEMENTS

This thesis is dedicated to David, Amy and Joshua. Their love and support has kept me going over the years.

My supervisors have each played an important role in guiding me along the way. I am particularly grateful to Dr. Barbara Gregson for helping me to develop an appreciation of statistical methods in the earlier stages of my work. She was always available for a chat when I needed it. Professor Jean Potts has provided a useful physiotherapy perspective, which has assisted me in developing the links between theory and practice. My director of studies, Professor Bob Heyman, deserves a special mention. His ability to critically review any subject has made me change my thinking on many occasions, and I have greatly valued his contribution to my work.

This work would not have been possible without the contribution of clients and carers and the generous grant from the Sainsbury Family Trust Foundation.

It was a privilege to work with the Domiciliary Physiotherapy Service staff. They all played an important role in helping me to understand the unique nature of domiciliary physiotherapy practice.

ABSTRACT

The aim of this research was to undertake an evaluation of domiciliary physiotherapy, by assessing the cost effectiveness of a new Domiciliary Physiotherapy Service (DPS) and by analysing the process of domiciliary physiotherapy practice. The main element of the work was a randomised controlled trial of the DPS, in which an experimental group receiving domiciliary physiotherapy assessment and intervention was compared with a control group receiving conventional care. Hypotheses that domiciliary physiotherapy would improve clients' independence in activities of daily living (ADL) and health status, and reduce clients' use of other services, were tested. The null hypotheses related to ADL and health status could not be rejected, possibly because of a smaller than intended sample size, and/or the masking of real effects by sample attrition, or lack of sensitivity of the outcome measures. There was evidence to suggest that the DPS may have significantly increased, rather than decreased, the proportion of clients with at least one contact with another health or social service. The analysis of the process of domiciliary physiotherapy developed as the RCT progressed. An interpretive account of domiciliary physiotherapy practice, framed within the author's own experiential knowledge, was constructed using quantitative and qualitative data from DPS treatment records, GP referral forms, and interviews with clients, carers and experienced community-based therapists. The interpretive analysis has underpinned a new 'reciprocal learning' model of domiciliary physiotherapy, which may assist practitioners working in the field. The way forward for domiciliary physiotherapy practice may be to acknowledge that measurable clinical outcomes cannot easily be determined, and that criteria for assessing the value of domiciliary physiotherapy should be based on client and carer perspectives.

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Appendix 13 Dawson P and Heyman B (1997) Evaluating community health services: conflict and controversy. *Health and Social Care in the Community*, 5, 225-60.

CHAPTER ONE

INTRODUCTION

1. OVERVIEW OF CHAPTER

This thesis reports on research which evaluated a new Domiciliary Physiotherapy Service (DPS) introduced in Newcastle upon Tyne in 1989. A randomised controlled trial (RCT) of the DPS, conducted between 1989 and 1991, assessed the cost effectiveness of domiciliary physiotherapy in relation to its impact on clients' performance in activities of daily living, perceived health status and use of other health and social services. At the end of the RCT, a reflexive interpretive analysis of the process of domiciliary physiotherapy was undertaken. This analysis integrated qualitative data obtained from a small number of clients and carers and experienced domiciliary therapists within a framework of the author's experiential knowledge and reflections. The reflexive analysis was developed slowly over time between 1991 and 1995, in parallel with the detailed analysis of the quantitative outcomes from the RCT. A peer-reviewed journal article, which discussed methodological issues that arose during the RCT, was written in 1996 and published in 1997. The final three years of this part-time PhD programme (1996-1999) were spent writing up the thesis, which was submitted in April 2000.

This introductory chapter will firstly set out the overall aim and objectives for the research presented in this PhD thesis. Then, in Section 3, selected literature relating to the field of domiciliary physiotherapy will be reviewed. The local background to the research will be discussed in Section 4. The literature review will include papers current at the time of the trial, as well as those published more recently, in order that developments over the decade since the beginning of the research programme can be reviewed. Key changes in the organisation of the National Health Service during this period will be briefly addressed, so that the shifting political and organisational context of the research can be illustrated. The literature review will

be presented under four sub-headings. Firstly, the history of physiotherapy will be discussed from perspectives relevant to the development of domiciliary practice. Secondly, the growth of domiciliary physiotherapy will be analysed, with particular reference to medical dominance and tensions between traditional models of physiotherapy and the requirements of community-based practice. Thirdly, domiciliary physiotherapy as a field of work will be examined. Finally, the evolution of professional knowledge in physiotherapy will be reviewed, so that the issues facing domiciliary physiotherapists at the time of the trial can be related to current debates about physiotherapy knowledge and expertise. The status of professional or 'expert' knowledge was largely taken for granted in the late 1980s, but has since come under scrutiny, both within the profession and by others, particularly the Government and service users.

Additional literature will be discussed later, at the most relevant point in the thesis. For example, key controlled trials involving physiotherapy are briefly discussed in the present chapter, and then re-examined from a methodological perspective in Chapter Two. Literature relating to measuring the outcome of physiotherapy is also considered in Chapter Two. The characteristics of clients referred to other domiciliary physiotherapy services are reviewed in Chapter Three, when sample representativeness is discussed.

2. OVERALL RESEARCH AIM AND OBJECTIVES

2.1 RESEARCH AIM

The aim of the PhD programme was to undertake an evaluation of domiciliary physiotherapy, through an assessment of the cost effectiveness of a new Domiciliary Physiotherapy Service and an analysis of the processes underlying domiciliary physiotherapy practice.

2.2 RESEARCH OBJECTIVES

2.2.1 To assess the cost effectiveness of a new Domiciliary Physiotherapy Service (DPS), for adult and elderly clients and their carers by means of a randomised controlled trial (RCT) which compared the DPS with usual care available in Newcastle upon Tyne.

2.2.2 To analyse the process of physiotherapy in a domiciliary setting by using quantitative and qualitative data to construct an interpretive account of domiciliary physiotherapy practice.

2.2.3 To develop a model of domiciliary physiotherapy practice based on the RCT and the interpretive account.

3. LITERATURE REVIEW

3.1 THE HISTORY OF PHYSIOTHERAPY

Regulated physiotherapy practice began in the late nineteenth century, when women trained in remedial massage formed an organisation that was later to become the Chartered Society of Physiotherapy (Barclay 1994). In order to gain respectability and credibility, the early founders of the profession invited the patronage of medical men of the time (Roberts 1994). Having doctors as role models motivated the profession to align itself with the practice and theory of medicine, and a strong association was formed between physiotherapy and hospital-based care. Like doctors, physiotherapists began to specialise in defined areas of practice, e.g. orthopaedics, neurology or surgery. They studied medical subjects such as anatomy and physiology, and made claims to scientific knowledge that were later to play a key role in the professionalisation of the occupation of physiotherapy (Hugman 1991). Physiotherapy practice

developed according to the framework of the medical model. Treatments were expected to provoke repeatable responses from human bodies that were believed to behave in predictable ways (Roberts 1994). Physiotherapists accepted that diseases and disorders could be explained in terms of changes or failures in body systems, and they did not consider that both response to and origins of illness could be accounted for in psychological terms (Pratt 1989). Physiotherapy was applied as a counter to disease or disability, with the aim of curing the patient or restoring abnormal function back to normal (Roberts 1994). The treatment of physical problems by physical means formed the core of physiotherapy (Williams 1986), and physiotherapists' use of their hands in treatment became the key element that distinguished them from other professionals.

At the time of the trial, physiotherapy held high status within the remedial therapy professions, by virtue of its command of technical skill and its close association with medicine (Alaszewski 1979). However, this association had brought with it dominance by doctors. By the 1970s, physiotherapists had started to question doctors' control over the scope of their practice, and were beginning to fight for clinical autonomy (Ovretveit 1985). In 1972, the Chartered Society of Physiotherapy made a significant move forward by appointing a physiotherapist as chairman, rather than a doctor (Barclay 1994). The right to manage themselves was finally acquired by physiotherapists following the 1974 National Health Service reorganisation, but the profession was still ideologically dominated by medicine. According to Alaszewski (1979), physiotherapists were technique-centred practitioners, more focused on their special skills than on the problems of the patient in their care. In his review of articles published in the journal of the Chartered Society of Physiotherapy between 1964-1973, he found that nearly 70% of papers were concerned with equipment, specific conditions or techniques of treatment, and only 22% were holistically orientated. He had previously observed that physiotherapists did not necessarily conceptualise patients as whole beings (Alaszewski 1977), but mentally deconstructed them into relevant constituent parts when planning treatment.

3.2 THE GROWTH OF DOMICILIARY PHYSIOTHERAPY

The first community physiotherapy service appeared in 1943 (Dennison 1969) when a mobile physiotherapy unit, funded by voluntary contributions, was set up in East Surrey. However, it was many years before physiotherapy outside hospital premises became widely available. The medical dominance once welcomed by physiotherapists had become a barrier to professional diversity. While other professions, such as nursing and occupational therapy, were developing community-based services in the 1960s and 70s (Burnard 1988), physiotherapy was fighting for professional autonomy. Many physiotherapists were managed by doctors. They could only see a patient on doctors' orders, and doctors prescribed the treatments they gave (Ovretveit 1985). Progress into the community was slowed down by hospital consultants striving to maintain exclusive control over and access to physiotherapy services. It was not until the 1970s that physiotherapists acquired the right of self-management (Ovretveit 1985) and the freedom to determine areas of development for the profession. However, even after self-management was in place, physiotherapy did not immediately extend its scope of practice.

There are several possible reasons why the profession was slow to diversify. Physiotherapists were used to high status within the professions allied to medicine, and the growth in community as the location for professional intervention was more marked in patient groups not usually associated with high status work, e.g. the elderly and people with learning disabilities (Hugman 1991). Community-based rehabilitation services for those with long-term impairments developed as the poor relation to hospital services, as the technical nature of medicine and physiotherapy did not fit well with the slow pace of recovery or inevitable decline of patients being managed at home (Robinson 1988). Advice and counselling are key components of successful long-term rehabilitation therapy, and the reduced need for the hands-on intervention so fundamental to physiotherapy may have been off-putting for highly trained therapists. Condie (1991) claims that physiotherapists back away from problems that cannot be tackled by conventional physiotherapy means, and that they feel guilty if they are not carrying out

technical treatment during every minute of a session with their patient. Paradoxically, although long-term rehabilitation does not assume high status, the work is probably more challenging than high-tech acute care (Hugman 1991). Caseloads in the community are likely to be diverse and demanding, and the support of other professionals cannot be immediately accessed as in a hospital situation (Smyth 1985). Therefore, community-based work provides considerably more scope than hospital work for physiotherapists to develop clinical freedom and autonomy (Alaszewski 1977). Outside a hospital base, physiotherapists have to decide who to treat and who not to treat. They must prioritise their caseload, rather than simply respond to referrals, and they may be required to take the lead on a case or co-ordinate the work of other professionals. Ironically, such levels of autonomy in physiotherapy are characteristic of fields where medicine has little to offer (Ovretveit 1985).

As physiotherapists become specialists, they may become inflexible and over-skilled, lacking the open-mindedness which would enable them to cope with problems that do not fit with their own frame of reference (Schon 1991). At the time of the trial, social scientists were beginning to argue that the medical model of rehabilitation could not be successfully applied in cases of intractable long-term impairment, where there may be no possibility of a cure or return to normal (Robinson 1988). This poor fit between traditional models of practice and the needs of community-based clients may explain why domiciliary physiotherapists can find it difficult to obvious places at which to begin or end their treatment (Furnell and Furnell 1987). While physiotherapists may be very familiar with working at the level of impairment to relieve pain or restore movement after an acute sprain or strain (Condie 1991), they are less comfortable working with incurable disability.

In the modern health service, we are now experiencing a substantial shift towards primary care led services. The White Paper *The New NHS, Modern, Dependable* (Department of Health

1997) has raised the profile of those working in the community. New Primary Care Groups will be responsible for commissioning services for local patients, and physiotherapists may have a unique opportunity to extend their role into primary care on a wide scale. However, this extension of role will bring with it new challenges in relation to moving away from medically orientated practice, relying less on purpose built environments and equipment, and learning to work more effectively with carers as well as patients. The physiotherapists working in the DPS responded to these challenges, and the resulting development of their practice will be discussed in this thesis.

3.3 DOMICILIARY PHYSIOTHERAPY AS A FIELD OF WORK

The expression ‘community physiotherapy’ was used loosely to describe any service offered in community venues such as GP premises, health centres, or the patient’s own place of residence (Partridge 1982a). However, more recent papers have begun to use the terms ‘home’ physiotherapy (Young and Forster 1992) or ‘domiciliary’ physiotherapy (Gladman *et al.* 1995) to distinguish between services offered in the patient’s own home and those offered in other non-hospital venues. The term domiciliary physiotherapy has been chosen to describe the service under investigation in this PhD.

In the 1970s, physiotherapy out of hospital sites became gradually more widely available. However, following reports by the Department of Health and Social Security (1972, 1973), domiciliary services that offered regular treatment for community-dwelling adults were discouraged, on the grounds of economy. Domiciliary physiotherapists were initially urged to take on an advisory role only. Over the last 20 years, several anecdotal papers have charted the growth of community/domiciliary physiotherapy for adult patients (Macmillan 1977, Frazer 1980, Lamont and Langford 1980, Forster *et al.* 1981, Smyth 1985, Burnard 1988, Seymour and Kerr 1996). It would seem that the recommendations of the early 1970s were later

disregarded, as papers from the 1980s, published before the trial, describe services that clearly offer treatment as well as advice (Frazer 1980, Smyth 1985, Burnard 1988). Some early services, such as the one reported by Smyth (1985), were developed, like the DPS, to meet the needs of multiple patient groups. However, as time has passed, services have become more targeted towards patients with a specific diagnosis, e.g. stroke (Forster and Young 1990).

Various papers report common aims in service provision, and, regardless of whether they were published in the 1980s or 1990s, they express similar views on the possible benefits of physiotherapy in a patient's own home. Most acknowledge the advantages associated with seeing the person in their own environment. In the home situation, problems linked to the living environment can be more easily determined, families can be closely involved and carers' problems may be more easily addressed (Ebrahim and Nouri 1987). Strategies for solving problems can be tested in the 'real' situation, rather than in the artificial setting of the hospital (Forster and Young 1990), although the lack of a purpose built environment and equipment does limit the range of treatments that can be offered. Evaluation of progress can be judged within the patient's own surroundings (Smyth 1985), and difficulties likely to lead to hospital admission can be detected early. In a survey of carers of elderly patients discharged from hospital (Williams and Fitton 1991), it was found that carer fatigue was a contributory factor in 48% of re-admitted cases. The provision of domiciliary physiotherapy may help to reduce carer fatigue, and thus reduce patient re-admission rates, by teaching carers safe and effective ways of moving and handling the person they are caring for.

Domiciliary physiotherapy may be the only feasible way of offering physiotherapy to some patients, as travelling to hospital can be difficult, or even impossible, for frail elderly people or those in constant pain. Travel time to hospital can amount to one and a half hours (Hildick-Smith 1985), and ambulance journeys have been shown to cause stress or sickness (Stokoe and Zuccollo 1985). A study of rehabilitation after stroke concluded that one third of patients were

too old or frail to make frequent visits to hospital for treatment after discharge (Shiekh *et al.* 1981). Although treatment at home may be more acceptable to the patient (Salvage *et al.* 1988), acceptability to the patient has to be balanced against the time spent travelling by the domiciliary physiotherapist, which, it has been estimated, takes up 8% of the working day (Burnard 1988).

Controlled trials that provide evidence about the effectiveness of domiciliary or home-based physiotherapy were not published until the 1990s, and are confined to the field of stroke rehabilitation. Key outcomes of these trials are discussed here, and methodological issues are considered in Chapter Two (Methods). Small, but statistically significant, differences have been shown between groups of patients treated by domiciliary therapy as against other methods of rehabilitation (Young and Forster 1992, Wade *et al.* 1992, Gladman *et al.* 1993). With regard to carer outcomes, no significant differences were found, on social engagement or life satisfaction measures, between carers of patients receiving domiciliary rehabilitation or those receiving routine hospital-based services after discharge (Gladman *et al.* 1993). Similarly, carers of stroke patients who received domiciliary physiotherapy have not been found to be significantly less stressed than carers of patients who attended day hospital (Young and Forster 1992). Trials of 'mixed' disease/disability groups have not yet shown significant differences between home-based and other methods of care (Laing *et al.* 1984, Eagle *et al.* 1991). Few recent trials report, in any detail, what it is that domiciliary physiotherapists do when they visit their patients. Wade *et al.* (1992) state that the greatest difficulty in rehabilitation research is defining accurately the intervention being studied. In trials of rehabilitation, the therapeutic process is often treated as a 'black box' since experimental research methodology tends to focus on outcomes rather than process. A review of scales of measurement appropriate to domiciliary physiotherapy is provided in Chapter Two (Methods).

Wade *et al.* (1992) are to be commended for giving a more detailed account of their physiotherapy intervention than is usually seen in reports of trials. However, the problem solving physiotherapy approach they cite is described largely in terms of physical interventions such as gait re-education and exercises. The complex interactions between professionals, patients and carers have not yet been adequately discussed in the UK physiotherapy literature, despite a call in the early 1990s (Richardson 1992a) for research to look at the actions, reflections and appraisals of practising physiotherapists, rather than the application of skill and technique.

3.4 EVOLUTION OF PROFESSIONAL KNOWLEDGE IN PHYSIOTHERAPY

This section will address the relationship between theory and practice in domiciliary physiotherapy, with particular reference to the growing awareness of the inadequacies of a frame of reference built solely on medical knowledge and dualist principles (Berg 1992, Roberts 1994, Thornquist 1995). Domiciliary practitioners have to cope with moving from a hospital based environment, where medical knowledge is regarded highly, into the social world of the client and carer, where private knowledge (Robertson 1996) and tacit skill (Richardson 1993) may be more important.

At the time of the trial, it had been suggested that domiciliary physiotherapy required therapists with broad-based knowledge and experience who were capable of working on their own and taking initiatives in isolated situations (Burnard 1988). The requirement for broad-based knowledge remains current today, although we are still struggling to define what that knowledge base should consist of. According to Eraut (1994) the pace of clinical practice allows practitioners little time or opportunity to examine the implications of theory for practice. Domiciliary practitioners are under pressure to make on-the-spot decisions in front of clients and carers, in an environment where they are detached from libraries and other information

resources. The propositional knowledge base of the physiotherapist, derived through research and scholarly activity, may become less important to them in practice than the everyday knowledge gained through experience. Schon (1987) concluded that professional practitioners from many fields of work deal with 'messy' problems where there may be an uneasy relationship between theory and practice.

The physiotherapy profession has begun to engage in a debate about the complexities of 'knowing'. Authors have compared and contrasted different forms of knowledge, such as that gained from academic study against that gained from experience and practice (Higgs and Titchen 1995). The technique-centred practitioner identified two decades ago by Alaszewski (1979) may still exist within the profession. Thornquist (1994, 1995, 1997) conducted detailed observational studies of encounters between patients and physiotherapists in Norway and found that physiotherapists practice with 'two worlds of knowledge'. Whilst practitioners possess specialised knowledge of the body and its systems, they use this knowledge in a very dualistic way, separating their clinical judgement of signs and symptoms from their everyday knowledge of people and how they live their lives. Thornquist (1994) asks the question *What kinds of knowledge do physiotherapists apply, and when do they apply it?* She concludes that physiotherapists use patients' stories of their problem only to confirm their own frame of reference and view of the problem, and selectively disregard other elements of information given by patients if they don't 'fit' with their diagnosis. In other words, physiotherapists have difficulties in connecting the 'two worlds' of diagnostic knowledge and contextual and personal client information in a truly integrated way. In her study of an encounter between a domiciliary physiotherapist and a husband and wife, Thornquist (1997) emphasises the predicaments that can be generated in a person's own home. She describes the power struggle observed between the husband and wife over the management of the husband's stroke, and suggests that diagnostic knowledge cannot be separated from the social process of the encounter.

At the time of the trial, domiciliary physiotherapy was a new and emerging discipline. Practitioners were coming to terms with their role and trying to develop an appropriate knowledge base to underpin their practice. This literature review has shown that evidence to support the development of domiciliary physiotherapy services was confined, at that time, to anecdotal papers and speculation within the profession about the likely benefits of physiotherapy at home. Since then, the political climate has changed, and the Government demands that practice be based on evidence from well conducted research (NHSE 1996), demoting expert opinion to the lowest form of acceptable evidence. Consequently, the divergence between what is taught or stated about physiotherapy practice and what actually occurs has become an issue for concern. Roskell et al (1998) have proposed that there is now a substantial theory-practice gap in physiotherapy, which threatens the future of the profession.

4. BACKGROUND TO THE STUDY

4.1 RESEARCH FUNDING AND THE ROLE OF PREVIOUS PILOT STUDIES

By 1980, 75% of districts had some form of community physiotherapy provision (Partridge 1982b). In 1981, a Government report *Physiotherapy in the Community and Open Access to Physiotherapy Departments for General Practitioners* (Department of Health and Social Security 1981) advocated the development of domiciliary physiotherapy to help keep elderly people in their own homes for longer. In Newcastle upon Tyne, the District Health Authority (DHA) responded to the Government review by implementing a pilot service, which was set up by the author of this thesis.

The pilot service provided assessment and treatment for housebound elderly/adult patients in Newcastle upon Tyne. Clients, carers and GPs who accessed the pilot service were very positive about the value of treatment in a homely rather than clinical environment. GPs stated

that, for just over half the cases they referred to the domiciliary physiotherapist, the usual course of action would have been referral to a hospital consultant or admission to hospital. This testimony suggested that the introduction of domiciliary physiotherapy would result in cost savings for hospital services, by averting the need for hospital admissions and consultant referrals. The recommendation following the pilot scheme was that domiciliary physiotherapy should be developed. However, there were no pump priming funds available to initiate the service. The DHA viewed it as a luxury they could not afford.

In 1988, The Sainsbury Family Trust Fund (a charity committed to developing family-orientated community services) approached Newcastle DHA with the offer of a grant of £300,000 to help develop some type of home-based care service. The pilot scheme mentioned above was submitted to their Trust Board as a potential new service, and the £300,000 was awarded to Newcastle, to help implement domiciliary physiotherapy.

4.2 RELATIONSHIP BETWEEN THE RESEARCH AND LOCAL POLICY MAKING

A project advisory group was set up by the District Physiotherapist (see Appendix 1 for list of membership of the advisory group) to plan how the grant money should be used, and, in the longer term, to make policy recommendations about future service development. The author acted as facilitator of the group. The group decided that the £300,000 should be used to fund a large-scale randomised controlled trial designed to evaluate the cost effectiveness of a new Domiciliary Physiotherapy Service (DPS). It was intended that the results of the evaluation would inform recommendations to Newcastle DHA about the future development of domiciliary physiotherapy.

5. SUMMARY

This chapter has provided an historical and contextual introduction to the research. Domiciliary physiotherapy has been revealed as an emerging discipline, somewhat apart from main stream practice. The randomised controlled trial mentioned above forms the main part of the research presented in this PhD thesis. Other key trials involving physiotherapy are considered further in Chapter Two, along with a review of methods of measuring physiotherapy outcomes. As the trial progressed, additional qualitative research was undertaken by the author in an attempt to open up the black box of domiciliary physiotherapy, and provide a basis for a model of practice. Several key concepts relating to the practice of domiciliary physiotherapy have been introduced in this opening chapter, such as medical control and holistic versus reductionist models of practice. A deeper analysis of literature in these fields can be found in Chapter Five, where an interpretive analysis of domiciliary physiotherapy process is presented. The development of the overall research and the aims and objectives for the PhD are now discussed in detail in Chapter Two.

CHAPTER TWO

METHODS

1. OVERVIEW OF CHAPTER

This chapter will begin with an account of the research philosophy, which underpinned the PhD programme. The implications of the author's multiple roles of researcher, manager and project co-ordinator will then be considered. A summary of the overall research aim and objectives for the evaluation of the Newcastle Domiciliary Physiotherapy Service (DPS) will be presented, followed by a detailed discussion of the methodologies used.

2. RESEARCH PHILOSOPHY

This section will discuss the epistemologies and paradigms that have underpinned the various stages of the research. The position of the author within the research process will be discussed in the first person, in order to provide a contemplative account of how researcher and researched interacted, and to tell the story of how my philosophical perspective widened. By explicitly referencing the role of 'self', the researcher becomes reflexive (Usher 1997a). Traditionally, reflexivity has been viewed as a problem to be overcome but more recently the value of reflexivity in practitioner research has been acknowledged (Reed 1995).

Epistemology can be defined as a way of knowing or understanding the world, and epistemological questions inquire about what should be viewed as knowledge (Usher 1997b). Particular paradigms or frameworks for guiding research tend to be associated with particular epistemologies (Atkinson 1995). Individual academic disciplines tend to be associated with a predominant paradigm which frames the type of questions that can be asked, dictates appropriate methodologies and specifies what does and does not constitute valid data (Usher 1997b).

At the start of this PhD programme, my epistemological standpoint was entirely positivist/empiricist. I believed that facts and beliefs were separate, and that there was a single truth that could be known (Kolakowski 1993). Consequently, the goal of my research was to proceed from hypothesis formation, through data collection, to the acceptance or rejection of hypotheses, in order to provide indisputable knowledge on which practice could be developed. I viewed research as a technical process within which certain universal methods were better than others. Experimental method, in particular the randomised controlled trial, was selected as the gold standard method by which to evaluate the DPS, and standardised quantitative scales were chosen as outcome measures. At the outset I thought that the data collected through these methods would be independent of interpretation and, if analysed in a scientific statistical manner, would yield the 'answer' to the research question.

However, as the research progressed, the outcomes did not appear to be yielding the definitive answers I expected. I found it difficult to remain distanced from the DPS therapists or their clients and carers to achieve the 'objectivity' normally required in positivist research (Kolakowski 1993). My experience as a domiciliary physiotherapist prior to the trial, and my role as DPS manager during the trial, had already served to shape the research hypotheses, and influence my interpretation of data and events. Furthermore, my perception of a single tangible reality began to blur, as I became aware of the multiple realities of therapists, clients and carers. As I started to search for information on the process as well as the outcome of domiciliary physiotherapy, I began to realise the capacity of the interpretive paradigm.

Interpretive epistemology rejects the universal logic of scientific discovery in favour of knowledge derived from the interpretation of human action and interaction (Rabinow and Sullivan 1979). In the interpretive paradigm, data are collected to generate meaning rather than uncover cause-effect relationships. Research in the interpretivist mode starts with data and generates hypotheses or theory from that data. I began to collect incidental data on the process

of domiciliary physiotherapy in an attempt to look inside the 'black box' of intervention, and by the end of my PhD programme I was able to use that data to help explain the phenomenon of domiciliary physiotherapy. This thesis has therefore been written to demonstrate how experimental and non-experimental methods have contributed to the overall evaluation of domiciliary physiotherapy. However it should be remembered that the central part of the planned PhD programme was a large scale RCT of a new Domiciliary Physiotherapy Service. The much smaller scale analysis of the process of domiciliary physiotherapy evolved later, and it served to extend my perspective as a researcher as much as to illuminate the outcomes of the RCT. By using multiple paradigms and becoming more reflexive I was freed to ask more questions than the RCT alone could answer (Guba and Lincoln 1989). No paradigm or perspective yields absolute truth and each will be presented critically as this thesis unfolds. It will be argued that the theory and practice of physiotherapy cannot be located in one paradigm (Parry 1997), as there will never be one correct version of the way things are (Halberg 1989).

2.1 THE AUTHOR'S MULTIPLE ROLES

From the beginning of this PhD programme I concurrently played three different roles: clinical manager for the DPS, overall project co-ordinator and higher degree research student. Furthermore, after the trial ended I left Newcastle Health Authority to take up an academic post, but remained responsible for the completion of data analysis and report writing. There were inevitable conflicts between roles. Early on in the research I realised how difficult it was to 'do research' independent of my roles as manager and co-ordinator, and at that time I began to be aware of the problems involved in assuming the neutrality associated with the positivist paradigm. However, there were also advantages in playing multiple roles. As a practitioner I was able to have an awareness of the attitudes and values associated with both service management and research, and to look realistically at the opportunities and constraints that one set of values imposed upon the other. For example, as service manager I was mentor to staff, and, through working closely with them, I gained substantial experiential knowledge of the

process of domiciliary physiotherapy practice. Later in the research, I came to regard my experiential knowledge as an important data source (Meerabeau 1995). It became a framework for the interpretive analysis of domiciliary physiotherapy presented in this thesis.

3. OVERALL RESEARCH AIM AND OBJECTIVES

3.1 RESEARCH AIM

The broad aim of the PhD programme was to undertake an evaluation of domiciliary physiotherapy, by assessing the cost effectiveness of a new Domiciliary Physiotherapy Service and by analysing the process of domiciliary physiotherapy practice.

3.2 RESEARCH OBJECTIVES

3.2.1 To assess the cost effectiveness of a new Domiciliary Physiotherapy Service (DPS), for adult and elderly clients and their carers by conducting a randomised controlled trial (RCT) to compare the DPS with usual care available in Newcastle upon Tyne.

3.2.2 To analyse the process of physiotherapy in a domiciliary setting by using quantitative and qualitative data to construct an interpretive account of domiciliary physiotherapy practice.

3.2.3 To develop a model of domiciliary physiotherapy practice based on the RCT and the interpretive account in 3.2.1 and 3.2.2.

4. OVERALL RESEARCH DESIGN

4.1 DESIGN CONSIDERATIONS

In order to fulfil the research objectives and meet the demands of the DHA, it was necessary to collect data for two distinct purposes:

- To inform policy and decision making about the provision of physiotherapy at local level.
- To construct knowledge and theory which would have applications, beyond the immediate context, to domiciliary physiotherapy in general.

A multi-faceted research strategy, informed by the principles of evaluation research, was therefore developed. Evaluation research has the capacity to both generate knowledge and inform decision making (Bond 1991). A pluralist approach (Smith and Cantley 1985) was used, where quantitative and qualitative data were combined.

4.2 EVALUATION RESEARCH

Evaluation research has evolved over the last 30 years or so and offers a wide variety of different strategies to assess the effectiveness and value of health or social programmes/services. St. Leger *et al.* (1992) offer the following definition of evaluation:

The critical assessment, on as objective basis as possible, of the degree to which entire services or their component parts (e.g. diagnostic tests, treatments, caring procedures) fulfil stated goals.

The reference to goals in the above definition indicates that there must be judgement of the service against a pre-determined standard, and according to St. Leger *et al.* (1992) this standard may be absolute or comparative. An absolute standard could be the evaluation of a service against stated targets, e.g. has an immunisation service succeeded in vaccinating 90% of the paediatric population? A comparative standard is likely to involve comparing the outcomes of a

new service against those of an existing one. In this case, it was not possible to specify an absolute standard against which to judge the cost-effectiveness of the DPS, as there was no agreement on what such a service should aim to achieve. Success was judged comparatively, by using a randomised controlled trial (RCT) experimental approach to compare the new DPS against existing usual care. A number of writers, from the 1960's to the present time, advocate the experimental approach to evaluation because of its emphasis on the rigorous comparative judgements that can be achieved through RCTs (Suchman 1967, Goldberg and Connelly 1982, St. Leger *et al.* 1982, Pollock *et al.* 1993, Wade 1995). The strengths and weaknesses of RCTs will be discussed further, later in this chapter. The requirement for objectivity, outlined in St. Leger's definition of evaluation, implies that there must be reliable and valid measures available to assess the value of any service, and that these measures must be free from the prejudices and biases of the researcher/evaluator. However, other authors (Becker 1971, Smith and Cantley 1985, Patton 1990, Chambers *et al.* 1992) have questioned the extent to which objectivity is either philosophically or practically possible. Moreover, relevant knowledge and information can be gained through more than just summative outcome measures and well-rounded service evaluation should examine process as well as outcome (Donabedian 1980, Patton 1987). Therefore, the evaluation of domiciliary physiotherapy extended beyond the experimental RCT model to include a small amount of process-orientated qualitative data and the researcher's own reflections. In this way some of the limitations of using experimentation alone were addressed. The different data sources were combined to produce an interpretive account of the process of domiciliary physiotherapy, which may help to illuminate the quantitative results of the RCT. In the following sections, the specific methods used to assess the cost-effectiveness of the DPS and to analyse domiciliary physiotherapy practice will be discussed.

5. METHODS USED TO ASSESS THE COST EFFECTIVENESS OF THE DOMICILIARY PHYSIOTHERAPY SERVICE

5.1 INTRODUCTION

In the following sections, the methods used to assess the cost effectiveness of the DPS will be discussed. The rationale for the randomised controlled trial will be presented, followed by the specific objectives of the trial. Experimental and control treatments will be described and then methods of sampling, outcome measurement, collection and analysis of data will be discussed. Immediately after the section on sampling there is a critical review of ethical issues relating to the trial. Further critique of the RCT methodology can be found in the final chapter of the thesis.

5.2 THE RANDOMISED CONTROLLED TRIAL

To assess the cost effectiveness of the DPS, a pragmatic randomised controlled trial (RCT) design was adopted. A group of patients receiving the DPS (experimental group) was compared with a group receiving usual care (control group). The main reason for selecting the RCT as a reliable and valid way of providing an assessment of the cost effectiveness of the DPS was its claimed ability to objectively and reliably 'test out' a new service or programme. Another important reason was that managers were more likely to view the research as having credibility and authority if it conformed to the 'gold standard' of experimental design (Abbott and Sapsford 1992). In theory, the strength of the RCT lies in the use of randomisation to provide two comparable groups, which differ only with respect to having received either the experimental or control treatment. Any differences between the two groups can then be confidently attributed to the independent variable (the method of treatment) because of the high internal validity of the research design (Pocock 1983, 1985; Bryman 1988; Altman 1991). To assess the cost effectiveness of the DPS, the RCT was designed according to a pragmatic, rather than explanatory, model. The following section will discuss the rationale for using pragmatic methods.

5.2.1 Rationale for pragmatic trial methods

RCTs have been used as a research method in medicine since the 1940's (Schwartz *et al.* 1980, Altman 1991). They were classically used to test whether or not a new drug reproduced in human subjects the results that were predicted by laboratory studies. The new (experimental) drug is usually compared with an old or placebo (control) drug and, throughout the trial, both experimental and control treatments are administered according to strictly defined protocols. These highly standardised experiments may be described as explanatory trials (Schwartz *et al.* 1980).

More recently, RCTs have been used to test treatments that can not be specified in the same way as the dose of a drug. Such trials, where experimental and control conditions have not been tightly defined and standardised, have been described by Schwartz *et al.* (1980) as pragmatic. They aim to test out a treatment/therapy in practice (rather than under artificial controlled conditions) and offer an opportunity to retrospectively study the process of the intervention, as well as the outcomes. Key differences between pragmatic and explanatory methods, as they would relate to trials of domiciliary physiotherapy, are summarised in Table 1.

Table 1 Key differences between explanatory and pragmatic trials of domiciliary physiotherapy (adapted from a table in Bond *et al.* 1989a).

	EXPLANATORY	PRAGMATIC
<u>Aim of trial</u>	To acquire knowledge and information about the differences between two treatments under ideal conditions.	To make a decision about which is the most appropriate treatment in practice.
<u>Definition of experimental treatments</u>	Frequency/duration of visits and treatment methods must be standardised and strictly defined in advance and adhered to for all clients.	Treatment may be flexible and optimised for the circumstances of each client (although an overall philosophy of care must remain constant in order that others can reproduce the service).
<u>Definition of control treatments</u>	A strictly defined usual treatment and/or no treatment/placebo.	Usual/existing practice judged to be the best available for the individual but excluding the experimental treatment.
<u>Criteria for assessing outcome</u>	Formal, observable clinical measures, which would be administered under identical conditions for each client.	Tests/measures should be of direct interest to the client, e.g. quality of life and administered under normal conditions, e.g. in client's own home.
<u>Choice of subjects</u>	Homogeneous (i.e. same type of clients). Should ideally be those especially likely to respond to the treatment.	Heterogeneous (i.e. diversity of type of clients). Should be representative of those likely to be referred to the DPS of which not all will stand to benefit from the treatment.
<u>Exclusions from trial</u>	Only clients who received physiotherapy treatment should be included in the analysis. Any clients referred and found inappropriate for treatment should be excluded.	No exclusions. If any clients allocated to the experimental group are found to be inappropriate for treatment, they should continue to be followed up and analysed with the rest, since in practice a service will receive inappropriate referrals.
<u>Method of comparisons</u>	Is there a difference between the two treatments? Standard statistical hypothesis test should be used.	Which treatment should be recommended in the future? Decision theory should be applied.

Whether a trial is pragmatic or explanatory, randomisation should ensure that two key criteria are met:

- The groups of subjects must differ only with respect to their treatment. In other words they must be initially comparable on all other important variables, although comparability may be later affected by sample attrition.
- The allocation of treatment to subjects must be carried out in an unbiased way (Schwartz *et al.* 1980, Altman 1991).

In an explanatory trial, two further criteria are also considered essential:

- The experimental and control treatments must be defined in advance, and there must be no deviations from defined treatments throughout the trial.
- The treatment should not be known to the patient (single blind trial) and, ideally, not known to the clinician either (double blind) to eliminate any factors which might influence the progress of the patient other than the experimental treatment (Pocock 1983).

The creation of 'blindness' in explanatory trials is thought to eliminate the possibility of Hawthorne effects (Pocock 1983) where the 'novelty' value of being in a trial or the unusual attention paid to the subjects may alter the outcome. The pragmatic model, which permits acknowledgement of the placebo effect as *a subsidiary psychosomatic treatment forming part of the context* (Schwartz *et al.* 1980), allows for the overt acknowledgement of the Hawthorne effect in the therapeutic process. The effect of client and/or therapist belief in the treatment being offered cannot be eliminated, as interaction between the two forms an intrinsic part of therapy. Even if the interactive element could be removed, it would mean that what was being tested in the trial was different from therapy offered in practice.

A pragmatic trial also differs from an explanatory trial in that therapeutic intervention (either experimental or control) can be adapted and optimised to suit the needs of the individual (Bond

et al. 1989). Complex interventions with psycho-social components cannot be standardised without destroying their therapeutic validity. In the DPS trial physiotherapists were able to offer intervention tailored to the needs of the individual client and carer and GPs were free to give whatever additional or alternative care they deemed appropriate for either the control or experimental group.

Pragmatic trials are now common place in health care evaluation. Various complex interventions have been tested by pragmatic methods. In psychiatry, social skills training has been compared with holistic health therapy in the treatment of schizophrenia (Wallace and Liberman 1985). Both interventions were defined simply as a 'multimodal approach to treatment' with differences in the form and content of individual programs. Home based care has been compared with standard hospital care, for patients with severe mental illness (Muijen *et al.* 1992). Home based care was carried out by community psychiatric nurses according to 'a problem solving approach' and standard hospital care meant the patient was given a bed and 'no special attention'. In primary care, 'health visiting practice' was compared with 'usual care' for elderly patients (Vetter, Jones and Victor 1984).

There are several examples of pragmatic trials in the field of rehabilitation. Key rehabilitation trials where physiotherapy forms all or part of the intervention will now be critically reviewed.

5.2.2 Review of pragmatic rehabilitation trials involving physiotherapy

One of the earliest trials of rehabilitation therapy compared an experimental intensive therapy group with conventional therapy and a no therapy control group for stroke patients (Smith *et al.* 1981). The experimental intensive treatment consisted of 6 months attendance at a rehabilitation department on four whole days per week for physiotherapy, occupational therapy and speech therapy. Conventional treatment involved attendance for the same package of therapy but only on three half days per week for 6 months. The control treatment consisted of

'regular' home visits by a health visitor, with referral to other services if necessary. Patients in the intensive therapy group showed the greatest improvement as measured on a 'modified activities of daily living index'. The beneficial effect of treatment was almost entirely achieved in the first three months and largely maintained for a year. There were no other patient outcomes except mortality and morbidity rates, which did not differ across the three groups. The final sample size of 133 patients may be comparable to that in contemporary trials but took six years to recruit. Changes in rehabilitation practice will inevitably have occurred over the long recruitment time, which raises concern about the reliability of the results. Although more women than men were originally recruited, a large proportion of women were excluded from the trial as they were too frail to cope with the intensive therapy regime, which casts doubt on the generalisability of the study. Key reasons for implementing domiciliary physiotherapy in Newcastle were to offer equality of access to physiotherapy and to overcome the problem of distress and discomfort suffered by older people during transportation to and from hospital on a regular basis. Smith *et al.* (1981) concluded that intensive therapy on an out-patient basis was realistic, although men were more likely to be suitable than women.

More recently, pragmatic trials of stroke rehabilitation have been designed to test domiciliary therapy against the more traditional hospital out-patient therapy model. Gladman *et al.* (1993) compared the functional ability and perceived health status of a large sample of 327 stroke patients treated by a domiciliary rehabilitation team or by routine hospital-based services, after discharge from three types of hospital care in Nottingham: health care of the elderly wards, general medical wards and a stroke unit. They took 16 months to recruit their sample. The domiciliary service included physiotherapy and occupational therapy, and was newly created for the study. A run-in period was allowed before the trial and, to enhance generalisability, the therapists visited services elsewhere to try to develop their service along similar lines to others operating in the NHS. Hospital-based services in the trial were those usually available in Nottingham at the time. The results indicated that stroke unit patients treated by domiciliary

therapy showed small but significant improvements in household and leisure activities as measured by the Nottingham Extended ADL Scale and on the Barthel ADL Index score at 6 months. Gladman *et al.* (1993) acknowledged the limitations of their pragmatic trial, i.e. that they were unable to identify the independent effects of the various types of treatment strategies used. However, they justified the use of pragmatic methods by arguing the case for testing therapies under realistic conditions and for separately analysing the outcomes of patients discharged from the three types of hospital setting. They concluded that domiciliary rehabilitation was a practical and effective alternative for younger patients with severe strokes discharged from stroke units. A sub-group of frail elderly patients appeared to do better with day hospital care, although the authors acknowledged that further research would be needed before any firm conclusions could be made. A trial in Bradford (Young and Forster 1992) had previously concluded that domiciliary physiotherapy was more effective and resource efficient than day hospital attendance for stroke patients.

The Bradford stroke trial (Young and Forster 1991) tested the effectiveness of home-based physiotherapy on its own, rather than as part of a planned package of multidisciplinary care. It compared an established home-based physiotherapy service with day-hospital care, using measures of functional ability, health status and carers' stress. The researchers chose pragmatic methods as they wanted to evaluate 'current clinical practices', rather than pre-determined treatment protocols. The nature of home physiotherapy was decided by the therapist within an upper limit of 20 hours treatment over 8 weeks (Young and Forster 1991). Records of both day hospital and home therapy were kept for retrospective analysis. A total of 108 patients were reassessed after 6 months and the results showed that although both groups had significantly improved in functional abilities after discharge from hospital, the improvements were greater for patients treated at home (Young and Forster 1992).

Domiciliary physiotherapy has been evaluated in a trial of home-based physiotherapy intervention for patients treated more than one year after a stroke (Wade *et al.* 1992). A

comparatively small sample of 94 patients entered the cross-over trial of immediate versus delayed physiotherapy. The results showed that a small but significant improvement in gait speed was achieved after 3 months treatment, but the improvement was not maintained at 6 months. Although Wade *et al.* (1992) state that the randomised, double blind trial remains the best design in treatment evaluation, they acknowledge the difficulties in achieving 'blindness' of observers in rehabilitation research, when patients and carers are likely to volunteer information on their treatment.

Multidisciplinary community based rehabilitation consisting of domiciliary physiotherapy, occupational therapy and speech therapy was compared with conventional out-patient care for 331 patients discharged from hospital early after stroke (Rudd *et al.* 1997). Individual objectives were set for each patient in the community rehabilitation group, and visits were made as frequently as necessary for a maximum of three months. Multiple measures of outcome were used, but at one year there were no significant differences between the two groups. The authors concluded that community rehabilitation was, therefore, no less effective than hospital-based care, and suggested that, with the increasing numbers of older stroke patients, the development of community based services may be the best way forward in order to reduce bed usage.

The trials reviewed above all have physiotherapy as the whole or a component part of the rehabilitation under scrutiny but they are all confined to the field of stroke care, making generalisability to the DPS trial difficult. Multidisciplinary rehabilitation trials involving physiotherapy in other fields have been slower to emerge, and none have focused on GP referred community-dwelling patients. Close *et al.* (1999) compared medical intervention and occupational therapy (with physiotherapy on referral when required) with conventional management initiated by the Casualty Officer for elderly patients who attended accident and emergency after a fall. A total of 397 patients were randomised, although 93 patients (23%) did not complete the study. The authors give little information on the characteristics of the drop-

outs, thereby casting doubt on the claim that the intervention group had significantly fewer falls than the conventional care group. Differential sample mortality could have caused a spurious result if, for instance, patients with more frequent falls dropped out of the intervention group.

Randomisation to different rehabilitation treatments has been shown to be practical and ethically acceptable in the trials reviewed (Smith *et al.* 1981, Young and Forster 1992, Wade *et al.* 1992, Gladman *et al.* 1993, Rudd *et al.* 1997, Close *et al.* 1999). Rudd *et al.* (1997) have claimed that results of pragmatic trials with broad entry criteria are generalisable to other settings and services. However, strict definition of therapy intervention is problematic (Wade *et al.* 1992) and may be undesirable in the real world of clinical practice (Young and Forster 1992, Gladman *et al.* 1993). Furthermore, as 'no treatment' placebo rehabilitation cannot ethically be given, patients will never be blind to whether they are receiving therapy or not. Assessors visiting patients' homes should be independent of the therapy treatment, and some authors have asserted that it is also feasible for assessors to be blind to which arm of a trial a patient has been allocated (Rudd *et al.* 1997). However, Wade *et al.* (1992) suggest that assessors may well pick up information from patients and carers about which treatment group they are in.

5.3 OBJECTIVES OF THE RANDOMISED CONTROLLED TRIAL

5.3.1 To assess the cost effectiveness of domiciliary physiotherapy.

5.3.2 To compare clients' self-reported performance on their level of independence in activities of daily living.

5.3.3 To compare clients' perceptions of their quality of life/health status.

5.3.4 To compare clients' use of other health and social services.

5.3.5 To classify clients recruited to the trial, in terms of demographic and clinical characteristics.

5.4 STRUCTURE OF THE RANDOMISED CONTROLLED TRIAL

The RCT was planned according to the fundamental principles of clinical trials (Friedman *et al.* 1996). Each subject was randomly allocated to either the experimental or control group, and followed prospectively from a clearly defined baseline, i.e. within one week of entry to the study. The new intervention being tested, in this case assessment and treatment from the DPS, was given to the experimental group (see section 5.5 for a detailed discussion of experimental group treatment). The control group was given usual care, as outlined in section 5.6. The effects of domiciliary physiotherapy on level of independence in activities of daily living and quality of life/health status were measured from baseline to the end of DPS intervention (or at 3 months if intervention was still ongoing), and then at 12 months. The impact of the DPS on use of health and social services was assessed by continuous follow up from baseline to 18 months. Figure 1 (presented in section 5.9 Methods of data collection in the trial) shows a flowchart of data collected at baseline, 3, 12 and 18 months.

5.5 THE EXPERIMENTAL TREATMENT

5.5.1 Definition of treatment in the experimental group

Clients allocated to the experimental group received, in their own home, a physiotherapy assessment (and treatment where appropriate) from a domiciliary physiotherapist. Physiotherapy was offered alongside any other treatment/service the client was already receiving.

5.5.2 The DPS team

Physiotherapy intervention was carried out by the DPS team, which consisted of 4.5 whole time equivalent Senior I Physiotherapists who were each in charge of a designated area of the City. They were supported either full or part-time by one of 3 Senior II Physiotherapists. A full time Physiotherapy Helper worked across all areas to assist the physiotherapists where necessary. A full-time Clerical Officer provided secretarial and administrative support to the

physiotherapists, and also managed the randomisation system. The author was overall project co-ordinator and line manager for the team. All project staff had a common office base.

Ideally, domiciliary physiotherapists should be experienced generalist practitioners (Seymour and Kerr 1996). However, at Senior I level, most physiotherapists have begun to specialise in medically defined areas of practice. The only experienced generalist the trial was able to recruit was the 0.5 part-time Senior I who, although previously a specialist in respiratory care, had worked for several years in a domiciliary service in another district. The full time Senior I staff were selected so that their individual specialities, together with the experience of the part time member, combined together to offer a composite generalist. One of the full time Senior Is was a specialist in stroke/neurological therapy, another had spent several years in rheumatology and acute care of the elderly, another had worked in a long term elderly care unit, and the final Senior I recruited had originally trained as a remedial gymnast and could offer a specialist perspective on the use of therapeutic/remedial exercise. The senior II staff were all physiotherapists who had previously rotated on a six monthly/yearly basis round a number of hospital specialities. The extent to which physiotherapy intervention was influenced by the previous experience of staff is analysed in detail in Chapter Five. Staffing and facilities were developed to provide sufficient resources for both a high quality service to clients and a thorough evaluation of the scheme. Bond *et al.* (1989a) have recognised that resources and commitment in a 'demonstration project' such as this are often higher than would be expected in normal practice.

5.5.3 *Piloting the service*

The project commenced with a two week orientation and induction programme for all staff. The aim of the programme was to familiarise staff with the 'community' environment, introduce them to the wider team they would be working with, and give them an opportunity to get to know each other. Other health and social service workers were invited in to speak about their

role and function. The team spent time getting to know each other, familiarising themselves with the geographical organisation of the service and studying the protocol for the trial. The possible effects of the induction period on the development of particular models of physiotherapy practice are discussed in Chapter Five.

Following the induction fortnight, the trial was introduced to GPs. Firstly, the trial was 'launched' at an open meeting, to which all GPs from the 57 practices within the Newcastle Health District boundary were invited. The author gave a formal lecture on the aims and protocol of the trial, and GPs were invited to ask questions. Display material was mounted in the room, showing physiotherapists at work in clients' homes. Although every GP did not attend, each practice sent at least one representative. After the open meeting a follow-up visit by a member of the DPS team was made to every practice, to allow GPs to ask further questions and to distribute information packs. It became apparent, after the open meeting and the follow-up visits, that there was considerable mixed feeling about the trial among the GPs. Although all were in favour of access to the DPS, some felt that the service did not need to be tested and should be implemented without research. Some were just glad of any access to physiotherapy, with or without research. Others were supportive of the research element as well as the access to service. The effect of these varying views on recruitment to the trial will be discussed later in this chapter in section 5.8.

My past experience led me to anticipate that making the transition from hospital to community based practice would not be without difficulties for staff, in terms of getting used to working in clients' homes and becoming a member of the community multidisciplinary team. Therefore, for a pilot period of four months (January - April 1989) prior to randomisation, the team assessed and treated a total of 299 pilot referrals from GPs and other primary health care team members. The purpose of the pilot period was to give staff an opportunity to adjust to practising physiotherapy in clients' homes. Regular team meetings were held, throughout the four month

period, to discuss treatment methods and approaches to client care. Staff were encouraged to present case histories and share with each other their early experiences as domiciliary physiotherapists. I attended these meetings and played an active part in discussion. As a participant, I gained valuable insight into how the staff were developing and what problems they were encountering. In hospitals, in-patients are 'at the disposal' of staff at all times. In the community, appointments for visits must be negotiated to both suit clients and minimise staff travelling time between homes. The therapists needed to adjust to working in the home of the client, without the purpose built environment and specialised equipment of the physiotherapy department. The routine presence of carers during treatment sessions was new for most staff. Being constantly watched as they worked was an initial source of anxiety. My experiential knowledge was used as a source of data for the interpretive account of the process of domiciliary physiotherapy (see section 6.4.5 later in this chapter). As already explained, the process of domiciliary physiotherapy was not prescribed in advance, but analysed retrospectively in a reflective way. However, for the purposes of the RCT, certain procedural elements were specified and written into a protocol prior to the start of the trial (see below). Deeper, subtler issues concerning the philosophy and model of physiotherapy practice came to light as the trial progressed and these are discussed in the final chapter of this thesis.

5.5.4 The DPS protocol

After the pilot period, a service protocol was agreed. Procedures for referral, minimum standards for assessment/treatment and roles/responsibilities are summarised below in points a) - l). Where appropriate, key differences between domiciliary physiotherapy and traditional hospital based practice are highlighted.

a) Referrals were accepted only from GPs, as they were given sole responsibility by Newcastle Joint Ethics Committee for seeking informed consent from clients to enter the trial (see section 5.7). Excluding other primary health care team members from making direct referrals was an

unfortunate, but unavoidable, departure from methods used in the pilot period. In practice, many district nurses overcame the restriction once the trial started by recommending to GPs that they refer certain clients. Making GPs solely responsible for referring patients undoubtedly reduced the number of referrals to the trial.

b) Urgent referrals were seen within the same or next working day at the discretion of the physiotherapist. Weekend cover, on an emergency basis, was offered for acutely ill clients already known to the DPS. In keeping with usual working patterns for physiotherapists in hospital, no new referrals were accepted at weekends.

c) Physiotherapy assessment and treatment was provided in the client's own home (including residential homes) and the physiotherapists worked as part of the primary health care team. The use of the home environment for assessment and treatment represented a major change from traditional hospital based in-patient or out-patient practice.

d) Each client was fully assessed by a Senior Physiotherapist. Assessments took account of the physical, social and psychological nature of the presenting problems. As discussed later (in Chapter Five) clients' physical problems were initially the main priority of the physiotherapists. As the trial progressed, and the model of practice of the therapists extended, social/psychological variables were considered more fully. For example, as previously hospital based practitioners, the DPS team were not fully accustomed to working alongside family carers. However, as the physiotherapists became more experienced, the needs of carers were more likely to influence assessment findings.

e) Records of all contacts with clients, including dates and details of assessment findings and treatment methods, were kept according to the Problem Orientated Medical Records (POMR) system (Petrie and McIntyre 1979). Identified problems were written down and numbered, and

progress was recorded in relation to each numbered problem. At the time of the trial, POMR was used across Newcastle Health District by all physiotherapists.

f) The team decided that treatment goals should be set in relation to problems identified in the assessment, and that these goals should be negotiated and agreed with each individual client. A physiotherapeutic management plan was devised and documented in each case.

g) Physiotherapy treatment consisted of many elements. The staff adopted multiple roles in the course of their work with clients and carers, e.g. hands-on treatment, education or advice, liaison with other primary health care team members, counselling and provision of equipment. Some issues related to the management of specific problems are discussed below:

- Where client problems were related to movement disorders (e.g. following a stroke), no single approach to treatment was specified. Instead, an eclectic approach using movement facilitation, movement re-education and exercise therapy techniques was favoured. To minimise disability caused by the movement disorder, physiotherapists could provide equipment such as walking aids and orthotic devices. Where carers were regularly moving and handling clients, instruction was given on the most efficient method, in order to minimise physical stress and strain for both client and carer.
- Acute musculoskeletal conditions, where pain or swelling were a problem, can, in a department setting, be treated by means of electrotherapy, e.g. ultrasound or low power pulsed short wave diathermy. However, since the team had limited access to portable electrotherapy equipment, manual techniques, therapeutic exercise and home use of a warm/cold application such as a hot water bottle or ice pack were more often used. Physiotherapy in the home setting necessitates a more simple, practical approach than that normally used in hospital.

- Respiratory conditions, such as chronic obstructive pulmonary disease or asthma, could, if indicated, be treated on a daily basis during acute stages. As in hospital-based practice, techniques such as percussion and postural drainage were used, along with breathing exercises. In the community, physiotherapists worked with GPs and District Nurses to teach clients correct use of inhalers and nebulisers, where appropriate. As the trial progressed staff realised the importance of teaching self-help techniques at an early stage, to avoid dependence on physiotherapy for clearance of chest secretions.
- Carers and clients were given advice and education where appropriate about the nature and progression of the problem, about how to prevent further deterioration, and about simple ways to cope with everyday difficulties. As the team became more experienced, communication skills, especially listening, became better developed. Many clients and carers, faced with permanent disability, need to talk through their feelings, hopes and fears. In contrast to their hospital based colleagues, the domiciliary physiotherapists saw clients at a later stage in the disease/disability, and in the environment in which they had to function. In this context, advice on long-term coping strategies becomes a priority. When in a client's home, staff were not distracted by the needs of other patients or demands of other staff. Time to talk, on a one to one basis with clients and carers, was a key feature of the DPS.
- Where appropriate, both family carers and primary health care workers were involved in carrying out and monitoring physiotherapy treatment, e.g. by carrying out simple movement/exercise programmes or checking progress. If another professional, such as a District Nurse or Community Occupational Therapist was involved, a joint visit could be arranged to facilitate communication regarding client treatment. Maintaining good communication links with colleagues was not always easy for domiciliary physiotherapists. Their usual practice of informally discussing cases with ward or clinic based staff, in the

course of their daily work, had to be replaced by early morning and lunch time telephone calls, or pre-arranged meetings.

h) Each Senior I and II Physiotherapist had their own case load and normally worked alone when visiting clients. If they needed assistance with client moving/handling the Physiotherapy Helper accompanied them on the visit. Clinical isolation has been cited as a cause of stress in domiciliary physiotherapy (Furnell and Furnell 1987). The DPS team tried to overcome the problems associated with working alone by having regular team meetings and setting aside time to talk to each other about caseload issues.

i) The Senior I physiotherapists were responsible for discussing case load and professional practice issues with their Senior II. Whole team meetings gave staff an opportunity to present case histories, and promoted sharing of ideas on the best way of managing client problems.

j) Where appropriate, the physiotherapists were able to refer clients to other health and social service workers. In the induction period, they had been introduced to the range of other services working into primary health care. In hospital based practice, the multidisciplinary team is much closer to hand and other professionals are likely to become automatically involved as patients are admitted to wards on which they usually work. The role of the DPS as a gatekeeper for other services will be returned to in Chapter Four.

k) Treatment was discontinued at the discretion of the physiotherapist. Follow-up review appointments were organised, or the client/carer was advised that they could contact either their GP or the DPS direct if the problem recurred. Physiotherapists in both hospital and community settings have clinical autonomy in decision making regarding cessation of physiotherapy intervention, and GPs were made aware that they were not responsible for prescribing either the type or the duration of physiotherapy treatment.

1) GPs were provided with telephone, personal, or written feedback on client progress. A letter of explanation was always sent if treatment was not indicated, when the client was discharged from regular physiotherapy, or if the clients subsequently referred themselves for further treatment. The GP was immediately informed if, during the course of physiotherapy intervention, the client developed new problems or deteriorated with respect to the presenting problem. Due to the developing nature of the service, it was particularly important to maintain these regular communication links with GPs, not only for the above reasons, but also to develop a process by which the GP could be educated about physiotherapy and his/her role as referrer to the service. In a ward situation the physiotherapist will 'bump into' the referring House Officer on a daily basis and will give up-dates as required. Most consultants invite physiotherapists to attend their ward rounds on a weekly basis, again making it easy for the therapist to give feedback on patient progress.

5.6 THE CONTROL TREATMENT

5.6.1 Definition of treatment in the control group

No domiciliary physiotherapy intervention was given. GPs could refer control group clients on to any other service/agency, already available before the introduction of the DPS. As in other pragmatic trials, the control group treatment was not defined in advance, other than to describe it as 'usual' or 'standard' care. The control group's use of other services will be discussed in Chapter Four. Services that were available to the GP are outlined below.

The only other way for the GP to gain access to physiotherapy was to admit the client to hospital, refer to a consultant, or advise the client to seek private physiotherapy. GPs were allowed, within the research protocol, to pursue any of these options. The earlier pilot scheme had revealed that these were unlikely courses of action for many clients, due to long waiting lists for consultants, or the clients inability to travel to out patient physiotherapy departments.

The GP could refer, as usual, to other primary health care team professionals such as district nurses, health visitors, social workers and occupational therapists. There was a long waiting list for social services occupational therapy (OT) and no health authority domiciliary OT service was available, therefore referral to OTs was unlikely to be frequently used as an alternative option to physiotherapy. It was anticipated that many control group clients would be managed by the GP alone, or by a district nurse if self-care was a problem.

5.7 SAMPLING

5.7.1 Theoretical and target populations

In any trial, the choice of sample should be made after the population to which the results of the trial will be applied has been defined (Schwartz *et al.* 1980). Defining the theoretical population helps the researcher to select a representative sample from which reliable generalisations to this population can be made. It was intended to generalise from the results of the trial to domiciliary physiotherapy services across the UK. For practical purposes, the sample was drawn from a target population of clients requiring domiciliary physiotherapy in Newcastle upon Tyne. The assumption was made that the population of clients and the treatments given in Newcastle, would be representative of those elsewhere in the UK.

5.7.2 Sampling strategy

In principle, representative samples are best obtained by random selection from the population (Altman 1991). In practice, this is rarely possible. The sample for this trial was chosen systematically, by accepting a consecutive set of referrals from GPs as a representative sample of clients requiring domiciliary physiotherapy. All GPs from the 57 general practices in Newcastle at the time of the trial were invited to participate. It was intended to recruit a large sample (800) in order to achieve representativeness, external validity and increase the power of statistical tests to detect statistically significant worthwhile differences if they existed (Altman

1991). From referral rates in the pilot scheme it was estimated that it would take approximately 6 months to recruit a sample of 400 experimental and 400 control subjects.

5.7.3 Criteria for referral to the trial

GPs were provided with guidelines for referral (see Appendix 2). These guidelines were developed after studying characteristics of clients referred to other domiciliary physiotherapy services (Frazer 1980, Smyth 1985, Burnard 1988) and reflecting on the experience of the pilot scheme. Suggested conditions suitable for referral were listed under the headings of respiratory, rheumatology/orthopaedic and neurological conditions, e.g. chronic asthma, degenerative joint disease, stroke. In addition, the guidelines also specified more general circumstances under which referral might be appropriate, namely:

- Clients who would find it difficult/impossible to travel to hospital for treatment.
- Clients whose problems were intrinsically linked to the home environment.
- Clients for whom carer support was required.

5.7.4 Formal inclusion and exclusion criteria

Formal inclusions and exclusions were kept to a minimum in order to maximise the generalisability of the results (Altman 1991). Men and women aged 18 and over, resident within the boundaries of Newcastle Health Authority, and referred to the DPS by their GP, were included. The only exclusions were clients with an identified learning disability or mental health problem, as community teams with access to physiotherapy were already in place to deal with the needs of these clients.

5.7.5 Allocation to experimental and control groups

Allocation to the experimental and control groups was by a process of random allocation, to minimise the possibility of intentional or accidental researcher bias when allocating clients to treatments (Altman 1991). Random allocation ensures that, at least initially, there will be no difference between the two groups (other than that occurring by chance) on any important

known or unknown variable. Any comparative differences in outcome can then be linked to the experimental treatment (Schwartz *et al.* 1980, Pocock 1983) within the limits of sampling error. Random allocation is central to the power of RCTs to uncover cause-effect relationships. However, true random samples are rarely maintained as trials progress, once clients begin to be lost from the trial (Cook and Campbell 1979).

5.7.6 Sampling and group allocation methods

All GPs were issued with an information pack (see Appendix 3) including the protocol and all necessary documentation for seeking informed consent and referring clients to the trial. GPs were asked to:

- a) Explain the purpose of the trial to the client.
- b) Give out a client information sheet.
- c) Obtain the client's consent to being put forward for random allocation.
- d) Obtain written consent from clients (or carers where the client was unable to do so) to enter the trial.

The above procedure was approved by the Newcastle Joint Ethics Committee and the Local Medical Committee (the GPs' representative body). At an earlier stage in the development of the trial methodology it was proposed by the advisory group that an alternative to randomising individual clients might be to randomise GP practices. Hypothetically some practices (chosen at random) would have had access to the DPS and others would not. The Local Medical Committee rejected the proposal as 'unfair' to those GPs who, having no access to the service, would have had to recruit clients purely for control purposes.

Random allocation to the control or experimental group was made using a 'computer-generated random number table'. The computer produced blocks of twenty number '1's and '2's in

random order, and each consecutive referral was given the next number in the block. If the next number in the block was a '1' the client was allocated to the experimental group and if it was a '2' the client was allocated to the control group. The research administrator kept the random number table, and no one else knew what the next number would be. GPs were encouraged to ring the administrator on a special telephone line while they were with the patient (either in the surgery or on a home visit) to obtain immediate feedback on the outcome of random allocation for that patient. They were asked to send on a referral form afterwards.

GPs were told which group the patient had been allocated to and that they were responsible for communicating the following to the patient:

- a) Whether the patient was in the experimental or control group, i.e. whether they were allocated to receive the new DPS or usual care.
- b) That a fieldworker would be visiting within a week to interview them.
- c) That a physiotherapist would be visiting either the same or the next day for urgent cases, or within a week for others (experimental clients only).

If the patient was allocated to the control group, the GP was reminded to proceed with the care of the patient as they would do normally, to preserve the nature of the control treatment as 'usual' practice.

A sample of 245 subjects was recruited in the 12 months from April 1989 to March 1990.

Recruitment to the study was closed after a year, because the research budget was not sufficient to fund an extended follow-up period. The size of the sample was well below the anticipated number of 800, and took twice the expected time period to achieve. Possible reasons for these recruitment problems will be explored within the discussion of ethical issues, in the following section.

5.8 ETHICAL ISSUES

As already mentioned, permission for the trial was obtained from Newcastle Joint Ethics Committee and the Local Medical Committee. The ethical issues relating to the trial will be addressed under four headings: risks, loss of therapeutic benefit, informed consent and distress/inconvenience to subjects.

5.8.1 *Risks*

In any research, whether experimental or not, the most important ethical principle is that no harm should come to the respondents as a result of their participation (Oppenheim 1992, Sim 1989). In the classical clinical drug trial, any potential risks to the experimental group from side effects of a new, untested treatment are of prime concern (Pocock 1983, Sim 1989). In this trial the introduction of a non-invasive treatment like domiciliary physiotherapy was unlikely to be actively dangerous, or have side effects for clients, provided therapists worked within their scope of professional practice.

5.8.2 *Loss of therapeutic benefit*

In any trial there is an inherent ethical issue regarding potential loss of therapeutic benefit to the control group, especially when it is believed that the experimental treatment is superior (Pocock 1983, Sim 1989). In this trial of domiciliary physiotherapy the control group were not offered domiciliary physiotherapy. However, to claim that an established, proven treatment was being withheld would be false. There had never been a DPS in Newcastle, and claims at that time about the value of domiciliary physiotherapy were based on descriptive pilot studies, speculation and precedents in other Health Districts, where services were being developed without evaluation. The control group clients were not deprived of any care they would normally receive from the GP. During the trial, one group of patients received the usual care offered by the GP and a second group received a temporarily available new service, for the purpose of testing its value.

However, GPs objected to random allocation of their patients to a control group. They claimed that, as doctors, they should have rights of access for their patients to the new DPS. Although the ethical problem of potential loss of benefit to control clients was raised by some, most GPs simply objected to loss of control over their patients' care. Some GPs feel it is unethical and damaging to the doctor-patient relationship for them to support randomisation of their patients into treatment groups which they do not judge as being the best for that individual (Korn and Baumrind 1991). The potential benefits of any new treatment have to be balanced against its risks or side effects. Much of the debate seems to be centred on trials of drug therapy or surgery for the treatment of cancer (MacIntyre 1991). Potential loss of therapeutic benefit was a major concern in trials where routine post surgical radiotherapy, for breast cancer, was withheld from a control group who received radiotherapy only in the event of a recurrence of symptoms (Schwartz *et al.* 1980, Pocock 1983). GPs referring to the breast cancer trial were alarmed by the potential negative effects of withholding what had previously been perceived as life saving treatment (Cancer Research Campaign Working Party in Breast Conservation 1983).

The work of Taylor (1992) may help in the analysis of reasons for poor recruitment of clients by GPs in the DPS trial. She surveyed physicians involved in a multicentre RCT in the USA and Canada, and she found that poor recruitment of patients was linked more to the social process of the RCT than to any inherent resistance or reluctance to support research. The physicians felt uncomfortable about random allocation taking over their decision making power and they disliked telling patients they did not know which was the best between the experimental and control treatments. Perhaps the Newcastle GPs also felt that their role as referrer to the trial conflicted with their role as the patient's doctor. The implications of poor recruitment are further discussed in the final chapter of this thesis.

5.8.3 *Informed consent*

All researchers have an obligation to offer potential subjects an understandable explanation and unbiased view of the research, so that they can decide, without pressure, whether to opt in or out (Sim, 1989). Initially, it was proposed to the ethics committee that the ‘randomised consent design’ (Zelen 1979), previously used in a trial of Nursing Home Care (Bond, Atkinson *et al.* 1989), should be used. In this design, suitable subjects are firstly randomised into either the experimental or control group and the GP seeks only the consent of those receiving the new experimental treatment. Research workers then seek consent, from both groups, for data collection and interviews. The randomised consent design was our method of choice for seeking consent from clients. It would have been simple and straightforward, as the GP would have only been responsible for asking experimental group patients if they agreed to an assessment by a physiotherapist. Trained fieldworkers would then have obtained consent for the research interviews and data collection. In the randomised consent model a group of clients would have been cared for in exactly the same way as usual, a second group would have consented to receive a new service and both groups would have consented to participate in a planned interview and data collection schedule.

However, although the randomised consent design may have been regarded as ethically sound in previous studies, the Ethics Committee rejected it. The committee insisted that the GP should be solely responsible for seeking the informed consent of all suitable patients *before* randomisation took place. The mechanisms for obtaining informed consent became an early source of concern and problems encountered are discussed below. Relying solely on GPs for referral of clients involved a significant departure from the pilot methods, and may have contributed to the low numbers of clients recruited.

When fieldworkers visited clients for the first interview it became apparent that, despite having received a protocol and forms for obtaining consent (Appendix 3), GPs had given clients many

different explanations of the trial. For example, some clients allocated to the control group were falsely expecting to be seen by a physiotherapist. Client dissatisfaction played a part in sample attrition, which is discussed in Chapter Three.

5.8.4 Distress or inconvenience to subjects

Fieldworkers made advance appointments, at the convenience of clients/carers, and all interviews were carried out in the clients own home to remove any stress or financial cost associated with travelling. Training was provided for fieldworkers on how to deal with interpersonal aspects of the interview situation (see section 5.9.2). As the health status questionnaire asked potentially sensitive questions related to level of disability, reliance on others, feelings of self-worth etc., fieldworkers were advised on how to deal with any emotional reactions from clients or carers. Confidentiality was assured at all times and clients were made aware that they could withdraw from the trial at any stage.

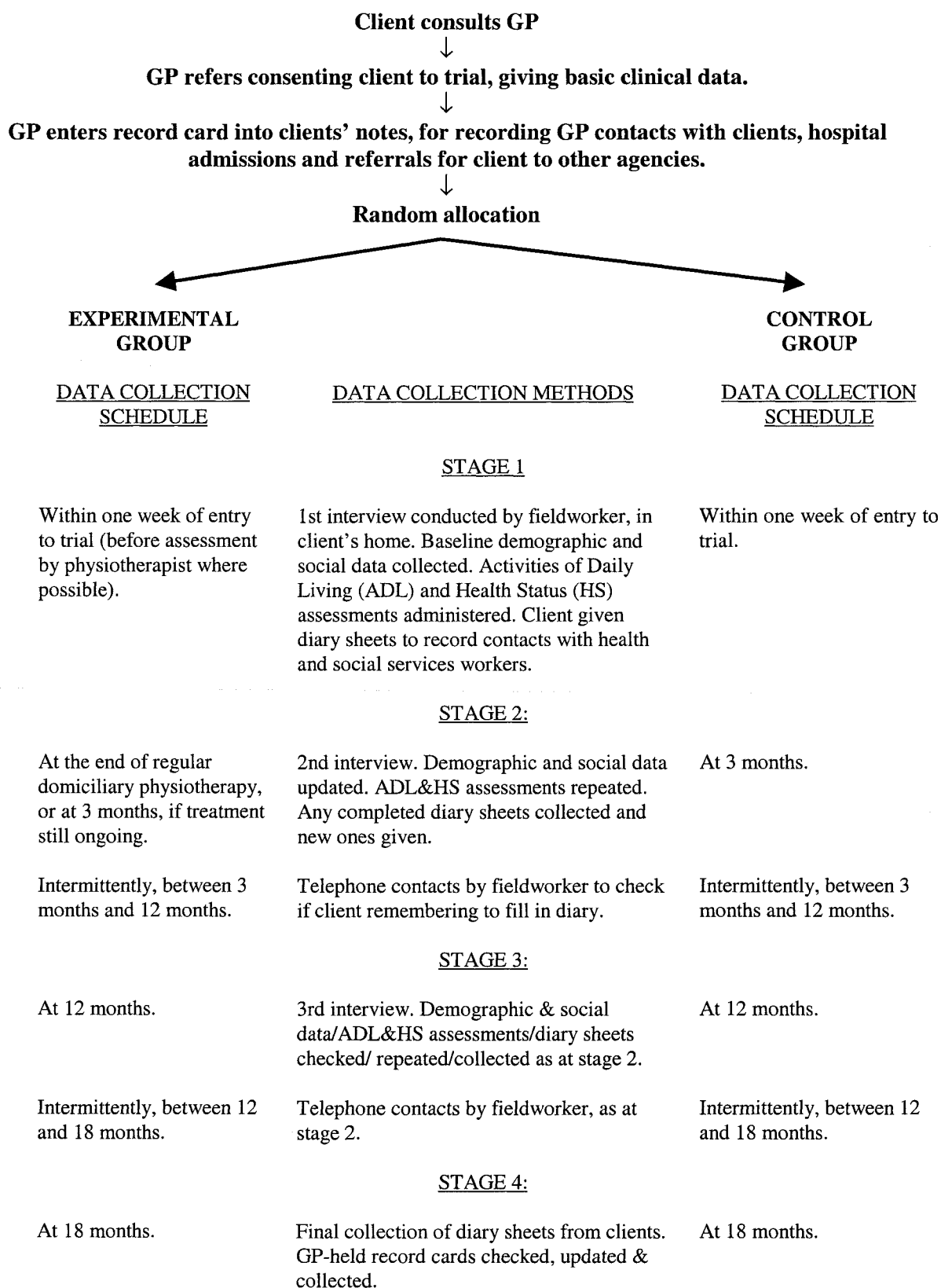
5.9 METHODS OF DATA COLLECTION IN THE TRIAL

In this section, there will be a brief outline of data collection methods (including a flowchart of the data collection schedule), an explanation of the role of the research fieldworker and a discussion of the rationale for use of the data collection methods.

5.9.1 Data collection methods

Data were collected using structured interviews with clients, client-held diary sheets, GP-held record cards, GP referral forms and physiotherapy case notes. Figure 1 (Flowchart of data collection) shows the data collection methods and time schedule for data collection. All subjects in the trial were interviewed by the research fieldworkers, at three stages, using the same structured interview schedule. A full account of the role and training of fieldworkers is given in section 5.9.2.

Figure 1 Flowchart of Data Collection Schedule



The interviews took place at the following times:

- Within the first week of referral, to provide baseline data (stage 1).
- At 3 months (or on discharge from domiciliary physiotherapy treatment in the experimental group), to provide interim outcomes (stage 2).
- At 12 months, to provide end point outcomes (stage 3).

The purpose of the stage 2 interview was to provide data on the short-term effects of domiciliary physiotherapy. It was, therefore, necessary to conduct the interview immediately after discharge from the DPS. In keeping with pragmatic methods the discharge point was not specified. In consequence, length of time from baseline (stage 1) to stage 2 was variable. It was decided that the stage 2 interview should not be delayed beyond 3 months after baseline, if the client was still receiving domiciliary physiotherapy, as 3 months had been shown to be the average length of intervention in the pilot study.

GP-held record cards and client-held diary sheets were filled in from entry to the trial for up to 18 months to provide data on use of other services. Because of the longer than anticipated time for recruitment, clients who were recruited in the later stages of the trial had a reduced follow-up time of between 12 and 18 months for GP and diary data. Other clients submitted their diaries early if they dropped out at the 3 or 12 month stage. A full analysis of sample attrition and the characteristics of drop-outs from the trial is given in Chapter Three. Table 2 shows experimental and control group mean and standard deviation follow-up times, firstly for all clients, and then with those who dropped out of the trial excluded. It can be seen from Table 2 overleaf that there was no significant difference between the experimental and control groups in length of follow-up time for data on use of other services.

Table 2 Follow-up times for use of services data, for experimental and control groups (all clients and drop-outs excluded)

	Mean (SD) follow-up time (months)	t-statistic and 2-tailed p value
<u>All clients</u>		
Experimental group n=114	14.1 (5.8)	t=0.95, p=0.35
Control group n=104	13.4 (6.1)	
<u>Drop-outs excluded</u>		
Experimental group n=87	16.9 (1.9)	t=1.02, p=0.31
Control group n=74	16.5 (3.1)	

5.9.2 The research fieldworkers

Three research fieldworkers were funded by the Sainsbury Trust grant. They were appointed on a part-time basis and selected because of their ability to communicate, rather than for any clinical or specialised knowledge. Their previous work backgrounds were in primary school teaching, social services and radiography. The role of the fieldworker was to carry out the interviews and monitor the completion of GP-held record cards and client-held diaries. They were responsible for arranging appointments with clients, communicating with GP surgeries and liaising with the physiotherapists about visits to clients in the experimental group. It was not possible for the fieldworkers to be 'blind' to whether clients were allocated to the experimental or control group, as clients often asked them to explain what the trial involved, after GPs had given misleading information or when clients had misinterpreted what the GP had said. The fieldworkers were instructed not to enter into discussion with the physiotherapists about client problems or the outcome of experimental group interviews. The reliability of the research would have been threatened if, as a result of any discussions with fieldworkers, the physiotherapist had altered their treatment.

Interview questions were standardised as far as possible. However, although questions were read out verbatim, clients often asked for clarification during interviews. Fieldworkers were

instructed to offer explanations to help clients understand the meaning of questions, but not to help them decide on their answers. To protect the internal validity of the research the fieldworker role was strictly confined to data collection. Although a good rapport between interviewer and interviewee can become therapeutic for the client (Oppenheim 1992), fieldworkers were cautioned not to offer any advice or assistance to clients or carers regarding the management of their problems, so as not to influence the success of either the experimental or control treatments. They were instructed to advise clients and carers to contact their GP in all cases where problems were raised. A two week training and orientation programme for the fieldworkers was provided.

5.9.3 Rationale for data collection methods

Interviews were used as the means of administering questionnaires on ADL and health status and collecting demographic and social information. Face-to-face contact with clients and carers allowed the fieldworkers to develop a rapport with them, thereby reducing the likelihood of non completion of the assessment schedule (Oppenheim 1992).

At the end of the first interview, fieldworkers introduced the diary sheets and showed clients how to fill them in. At subsequent interviews, fieldworkers checked the diaries, and clients and carers could ask questions or discuss any difficulties encountered when filling them in.

Informal telephone calls were made to clients between interviews to remind them to keep their diary sheets. The personal contact already established during interviews made follow-up telephone calls more acceptable to clients.

The questionnaires yielded largely quantitative data, and could have been administered by post. However, getting to a post box may have been difficult for some clients and the return rate for postal questionnaires is often below 50% (Oppenheim 1992). In any event, clients would have needed explanation about how to fill in the diary sheets, which would have been difficult by

letter, and the personal contact of an interview increases the individual's motivation to respond. Additional data on use of other services were collected by GPs, using booklets inserted into patients' notes. The reliability of using GP held records is discussed more fully later in this chapter.

5.10 METHODS OF OUTCOME MEASUREMENT

This section will begin with a short discussion of the concept of cost effectiveness and how it has been applied to the trial. Outcome measurement tools used to measure each objective of the trial will then be discussed in terms of methods of administration, pilot work carried out and reliability and validity.

5.10.1 The concept of cost effectiveness

The term 'cost effectiveness' is sometimes used interchangeably with the term 'cost benefit' (Chambers *et al.* 1992). Both these terms seem to share a common meaning, i.e. they refer to the financial implications (costs) associated with the outcome (effectiveness or benefit) of health and social programmes. However, they differ in that a cost benefit analysis (CBA) defines outcome or benefit in monetary terms, while a cost effectiveness analysis (CEA) uses assessments of outcome that have no monetary value attached (Richardson 1992). In a CBA, attributing costs to outcome or benefit facilitates the calculation of a simple ratio equation, from which the degree to which benefits exceed costs can be judged. Attempts to cost quality of life have included parameters such as the value of lost future earnings, or court awards for illness/disability. In health care, programme or service outcomes are very difficult to determine in monetary value, making the CBA often inapplicable or misleading (Carr-Hill 1989).

In the present study, the overall research design has been primarily influenced by methods of evaluation research, as discussed earlier in this chapter. The concept of cost effectiveness, rather than the technical model, has been used to provide a framework for selecting measures of outcome of the DPS. Costs were inferred by assessing whether or not the introduction of the

DPS reduced or increased the use of other services (Drummond and Ward 1988). Effectiveness was assessed by measuring any differences, in health status and independence in activities of daily living, between the clients receiving the DPS and those receiving usual services. The results were used pragmatically to make a practical judgement of cost effectiveness.

5.10.2 Measuring the outcome of physiotherapy

Measurement of physiotherapy outcome was reviewed by Partridge (1982), who suggested that outcome could be measured at three levels: localised tissues, e.g. swelling of an injured joint (level 1); performance of movement, e.g. amount of flexion at a specific joint or ability to walk a few steps (level 2); performance in daily life, e.g. function at work or in the home (level 3). Partridge's level 1 seems to be closely associated with the World Health Organisation (WHO) (1980) definition of impairment as:

... any loss or abnormality of psychological, physiological, or anatomical structure or function ... disturbances at the level of the organ.

Level 2 partly relates to the WHO definition of disability as:

... any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being ... disturbances in ... personal care ...in the performance of other activities of daily living, and in locomotor activities.

Level 3 refers to handicap, defined by the WHO as:

... a disadvantage for an individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal ... for that individual ... thus represents socialisation of an impairment or disability.

It has been argued by several authors (Jaekel *et al.* 1986, Tallis 1987, Deyo 1988, Sim 1989) that any change at the level of impairment, such as an increase in range of movement at a joint,

may be worthless unless associated with change recognisable to clients, at the functional or lifestyle level. As stated by Jaeckel *et al.* (1986):

... it means little to a patient whether he has three or six swollen joints, or whether his sedimentation rate is 20 or 30. He only desires to be as free from pain as possible, to be able to earn his own living, and to play an active part in social life.

The ability to live independently with a good quality of life and health status was likely to be very important to clients recruited to the DPS. Therefore, it seemed logical to choose to measure outcomes at the disability or handicap level, not at the level of impairment. As there may be poor correlation between a patient's capability in hospital and his/her performance at home (Andrews and Stewart 1979) the client or carer report was judged to be a more appropriate and meaningful measure of functional independence than a 'one off' test or observation in a clinical setting.

Disability/handicap outcome measures for assessing physiotherapy or other rehabilitation therapy interventions are widely reported in the literature. However, they have largely been developed and tested with reference to specific disease or diagnostic group. Examples include motor assessments (Ashburn 1982) and activities of daily living scales (Nouri and Lincoln 1987) for stroke patients; pain and disability scales for back pain sufferers (Fairbank *et al.* 1980); health status measures for arthritis research (Liang *et al.* 1985). The pilot scheme had already shown that the range of diagnostic groupings likely to be referred to the trial could range from general non-specific mobility problems of the frail elderly, to neurological conditions such as stroke or multiple sclerosis, and respiratory diseases, e.g. asthma or bronchiectasis. It would have been impractical to use different measures for different clients. Global measures, sensitive enough to pick up changes in mobility related independence and health-related quality of life were required.

5.10.3 *Measuring activities of daily living*

It was difficult to find a standardised measure of level of independence in activities of daily living that could encompass the variety of types of client likely to be referred to the trial. There were very few scales validated for use with a multi-diagnostic group. Two long standing, well known scales were considered: the Katz Index of Activities of Daily Living (Katz et 1963); and the Barthel Activities of Daily Living Index (Mahoney and Barthel 1965).

The Katz scale summarises performance in six functions: bathing, dressing, toilet, transfers, continence and feeding. The Barthel scale assesses performance across a wider range of 10 items: bowels, bladder, grooming, toilet use, feeding, transfers, mobility, dressing, stairs and bathing. The scales differ in that the Katz scale is hierarchical, and the Barthel summed. Katz devised the scale assuming that the various ADL abilities were recovered by patients in a specific and invariable order (Eakin 1989). Individual test items form a series with the supposed least difficult (and therefore presumably quickest recovered) tasks tested first. It was developed originally as a survey instrument to chart the course of chronic illness, and has been used mainly in the USA. The Katz index was not chosen because a hierarchical scale can yield unreliable results if the population of patients studied does not follow the same pattern of recovery as the scale predicts.

The Barthel Activities of Daily Living Index was selected for use in this study. It was originally designed to be used with a generic chronically sick group, rather than any specific diagnostic category. In its modern format (Collin *et al.* 1988), the Barthel Index has 10 items (as listed above) and a score ranging from 0 to 1, 2 or 3 can be awarded for performance in each item, based on the level of independence with which the task has been performed. A minimum of 0 and maximum of 20 is possible, representing a continuum from 'dependence' to 'independence' on the 10 items, which are not presumed to be in hierarchical order. Although a summed scale was viewed as more appropriate than a hierarchical one, the meaning of scores should be

treated with caution. A score of 10 out of 20 does not represent 50% ability or disability, and two individuals each scoring 10 may have different capabilities, depending on the items from which they have lost and gained points.

Nevertheless, the Barthel Index has been recommended as a robust and reliable clinical measure by Collin *et al.* (1988) who found high inter-observer reliability when comparing Barthel Index scores obtained from nurses' judgement, occupational therapists' observations, and patients' self-report. The validity of the Barthel Index has been reviewed by Wade and Langton Hewer (1987) and Wade and Collin (1988). They claim it has face and content validity, as it appears to measure items widely accepted as important in ADL. Scores on the Barthel have been shown to correlate closely to several other measures, e.g. extent of motor loss, mortality, and clinical judgement of severity of stroke. The Barthel Index has become a very popular tool, and has been used as an outcome measure in several rehabilitation studies where physiotherapy and/or other therapies have been evaluated, e.g. Granger *et al.* (1979) and Young and Forster (1992). According to Wade and Collin (1988), it has probably been used in more research, covering a wider range of conditions, than any other single index. The Barthel Index has also been recommended in critical reviews of ADL scales (Eakin 1989, Law and Letts 1989). Its widespread use in the UK at the time of the trial was an important factor influencing selection of the Barthel Index as an outcome measure. Using scales already validated and in general use facilitates uniformity and comparability between research (Tallis 1987).

At the time of the trial, the usual method of administration of the Barthel Index in other studies was by observation or interview. Using guidelines published by Collin *et al.* (1988) (see Appendix 4) clinical staff could judge client ability after observing them perform each task, or ask the client questions about how he/she performed each item. More recently, consistency has been shown between postal questionnaire, telephone interview and face-to-face interview

methods of administration (Yeo *et al.* 1995). The guidelines for scoring were adapted for the DPS trial into a standardised questionnaire format to be administered during interviews, so that fieldworkers did not ask questions in different or leading ways. Forced choice questions were devised to elicit the necessary information required to award a score for each item. These questions were tested by videotaped 'dry run' interviews in volunteer clients' homes, during the pilot phase before the trial. Interviewer performance and clients responses were reviewed using video playback. Any ambiguities or inadequacies in question wording, or problems in question ordering were noted. For example, the original scoring sheet starts with bladder and bowel function. We found that it was better to begin questioning with something less personal, such as mobility, to give both the client and interviewer a chance to get used to each other before focusing on bladder/bowel habits. A final version of the questionnaire was re-tested on videotape, and the scoring guidelines were used afterwards to award scores based on client yes/no responses. The videotape of the final test interview was used during fieldworker training. The Barthel Index questionnaire (see Appendix 5) was subsequently used as the assessment of ADL ability and administered by fieldworkers as part of the structured interview at stages 1,2 and 3 (see Figure 1). The main aim was to assess function from the client's perspective, but fieldworkers obtained the carer's report if the client could not communicate.

5.10.4 Measuring health status/quality of life

Measures of quality of life/health status are much less likely to be diagnosis specific than measures of ADL. Tools such as the General Health Questionnaire (Goldberg and Hillier 1979) are used widely as outcome measures in clinical practice and research. However, many have been designed for use in the USA, e.g. the Life Satisfaction Index (Neugarten *et al.* 1961) and the Philadelphia Geriatric Centre Morale Scale (Lawton 1975). The Nottingham Health Profile (NHP) was chosen for the DPS trial because it was developed in the UK as a measure of how health status affects quality of life (Hunt *et al.* 1986). The profile has been tested for face, content and criterion validity and has been understood and accepted by elderly respondents

(Hunt *et al.* 1980). NHP scores have successfully differentiated between 'sick' and 'healthy' people over 65 years old (Hunt *et al.* 1980) and between consulters and non-consulters in general practice (Hunt *et al.* 1981). The test-retest reliability of the NHP has been successfully demonstrated by high correlations between two scores obtained within four weeks of each other for people with persistent chronic conditions, e.g. osteoarthritis of the hip (Hunt *et al.* 1981) and peripheral vascular disease (Hunt *et al.* 1982).

The NHP is a two part, self-administered questionnaire (see Appendix 5). Part one asks the respondent to agree or disagree with 38 statements, presented in mixed order, relating to the following six domains: sleep (5 statements); energy (3 statements); emotional reactions (9 statements); social isolation (5 statements); physical mobility (8 statements); and pain (8 statements). The domains, especially physical mobility and pain, seemed highly relevant to the assessment of physiotherapy intervention. Part two of the NHP is designed to assess the number of aspects of daily life which are affected by health problems. Although there was some doubt about the applicability of some of the part two items, e.g. work and employment, for a largely retired sample, it was included in case some items proved useful. Part two of the NHP was later disregarded, as many clients found items difficult to respond to. Part one was analysed on its own, a procedure which does not affect the validity of the profile (Hunt *et al.* 1989).

The NHP was included in the structured interview schedule at stages 1, 2 and 3 (see Figure 1). The self-administration method recommended by the authors was used. After answering the Barthel Index questions, clients were asked to complete the NHP. During piloting, it was found necessary to produce an enlarged version of the profile, for clients with visual problems. The fieldworkers were instructed not to read the statements out unless absolutely necessary, so as not to influence client responses. The profile was omitted for any client with an apparent comprehension problem. Comprehension was judged subjectively by the fieldworkers at the

time of the interview according to whether the client seemed able to understand and complete the questionnaire.

5.10.5 Measuring clients' use of health and social services

Clients were given diary sheets (see Appendix 6) at the first interview and were asked to make an entry every time they were visited by a health or social service worker other than the GP. GPs were given supplies of special record cards (see Appendix 7) to insert into the clients' medical notes after referral to the trial. These record cards were to be used by GPs to note all their domiciliary and surgery contacts with clients, client admissions to hospital and referrals made for clients to other professionals. The client diaries and GP record cards were kept for a follow-up period of up to 18 months. Variation in follow-up time for use of services data has been considered previously, in section 5.9.1, Table 2.

5.10.6 Client diary sheets

Diary sheets were given to clients and carers in a folder. The term 'diary' is used to refer to a daily record of clients' contacts with other professionals, not a journal of personal activities or thoughts. Diaries are common place in social research, and are particularly appropriate for 'summing' activities over a long period of time (Oppenheim 1992). Clients were likely to have contact with a range of health and social services and, as there was not any central record of their care, it was not possible to obtain information on contacts with services in any other more 'objective' way. Clients were given a covering set of instructions (see Appendix 6), listing the relevant workers they might come into contact with, and an example of how to complete the diary. Each diary sheet had columns for recording the date, length of time and professional identity for each contact. Fieldworkers checked the sheets at each interview visit and made intermittent telephone contacts in between interviews (see Figure1) to help maintain client and carer motivation to keep the diaries up to date (Oppenheim 1992). The diaries were collected from the client/carer at the end of the follow-up period. The purpose of the diary sheets was explained to other community based professionals during the initial launch of the trial, to avoid

confusion or suspicion if they were shown them when visiting a client. The diary sheet system was tested during the pilot period before randomisation, and good co-operation was achieved from clients, carers and other community professionals.

5.10.7 GP record cards

GPs placed record cards with a highly visible orange strip on the top (see Appendix 7), into the medical notes of every patient they recruited to the study. The orange strip protruded from the top of the patient notes, to quickly identify to the GP that the patient was in the trial. GPs were asked to use the cards to keep a record of dates of their domiciliary and surgery contacts with patients, referrals made to other agencies and any episodes of hospital admission. Fieldworkers removed them from the GPs' surgeries at the end of the follow-up period.

The purpose of the record cards was explained to GPs during the launch of the trial, and varying attitudes were expressed towards the task of completing record cards. Some GPs admitted outright that they would not have the time or inclination to keep these extra records. Others said they would ask receptionists to fill in the record cards, and some were happy to fully comply. The disincentive of extra work has previously been suggested as a possible reason why GPs fail to recruit patients for trials (MacIntyre 1991). Client consent included consent to fieldworkers having access to their GP-held medical notes and, at the end of the follow-up period, fieldworkers retrospectively checked the record cards against the medical notes.

5.11 DEMOGRAPHIC AND SOCIAL CLASSIFICATION

Demographic and social data were collected from clients at each of the 3 interviews by asking standardised questions about age, gender, housing tenure, carer details and home help support (see Appendix 5). The conventional method of measuring social class by occupation was problematic for a sample likely to consist mainly of retired people. It was particularly

inappropriate for elderly women, who are classified according to their husbands' last occupation. Therefore housing tenure was chosen instead as a measure of social status. In a longitudinal study of socio-demographic mortality differentials, it was found that housing type (owner-occupied, privately rented or local authority rented) related significantly to residents' mortality (Fox and Goldblatt 1982). Clinical data, such as diagnosis and presenting problem, were obtained retrospectively from referral forms completed by the GP (see Appendix 3) and physiotherapy treatment notes. The International Classification of Diseases (ICD) (World Health Organisation 1977) was used for coding and categorising clients into diagnostic groupings. From the ICD classification, diagnoses were further grouped into categories used in other studies of domiciliary physiotherapy. The social, demographic and clinical variables were used to classify clients in order to assess the representativeness of the sample, and to test that random allocation had been successful in creating two comparable groups.

5.12 ANALYSIS OF RANDOMISED CONTROLLED TRIAL DATA

The analysis of the trial data focused on the quantitative differences between the experimental and control groups at the 3 month and 12 month stages. The following hypotheses were tested:

- Domiciliary Physiotherapy will improve level of independence as measured by the Barthel Activities of Daily Living Index.
- Domiciliary Physiotherapy will improve health status as measured by the Nottingham Health Profile.
- Domiciliary Physiotherapy will reduce use of other health and social services.
- Domiciliary Physiotherapy will reduce the number of GP referrals to other agencies.
- Domiciliary Physiotherapy will reduce the number of episodes of respite care and mean length of respite care stay.
- Domiciliary Physiotherapy will reduce the number of hospital admissions and mean length of hospital stay.

6. METHODS USED TO ANALYSE THE PROCESS OF DOMICILIARY PHYSIOTHERAPY

6.1 INTRODUCTION

The following sections will discuss specific objectives for analysing the process of domiciliary physiotherapy, the rationale for using multiple methods and the influence of the interpretive paradigm. Methods of sampling, perspectives on analysis and the application of a reflective analysis based on the author's experience will also be considered.

6.2 OBJECTIVES OF THE ANALYSIS OF THE PROCESS OF DOMICILIARY PHYSIOTHERAPY

6.2.1 To investigate GPs' diagnoses and reasons for client referral, as a basis for understanding why physiotherapy was indicated.

6.2.2 To provide a quantitative analysis of the number of visits made by physiotherapists and the duration and number of episodes of physiotherapy intervention given to clients in the experimental group.

6.2.3 To gain insight into client and carer perceptions of the role and value of domiciliary physiotherapy.

6.2.4 To investigate the views of experienced community based physiotherapists and occupational therapists (not involved in the DPS trial) on their experiences of community-based therapy practice.

6.2.5 To undertake a reflexive analysis grounded in personal experiential knowledge, in order to help develop an interpretive account and theoretical model of the process of domiciliary physiotherapy practice.

6.3 RATIONALE FOR USING MULTIPLE METHODS TO ANALYSE THE PROCESS OF DOMICILIARY PHYSIOTHERAPY

The outcomes of rehabilitation trials tend to be reported with little more than a brief description of the process of intervention being tested (Wade *et al.* 1992). Rehabilitation therapy has been termed a ‘black box’ and its conceptual contents are thought to be inaccessible. The backdrop of the RCT of domiciliary physiotherapy therefore provided a unique opportunity to begin to analyse the process of domiciliary physiotherapy and to look inside the black box. Multiple perspectives have been applied in the analysis, using quantitative and qualitative data.

Qualitative data on GPs’ diagnoses and reasons for referral were obtained from the GP referral form, and quantitative data on number of visits, duration of each course/episode of treatment and number of treatment episodes were obtained from physiotherapy treatment notes.

Qualitative research strategies allow the meaning of domiciliary physiotherapy to be explored from varying perspectives (Field and Morse 1985). In-depth interviews were conducted with two purposively selected clients and their carers to provide an insight into client and carer perspectives. As previously stated, the motivation to collect such data came from the researcher’s growing awareness of the limitations of the RCT and interest in the process of domiciliary physiotherapy practice. Data from two clients and carers does not constitute an in-depth qualitative study of client and carer perspectives. Experienced therapists views were investigated through a focus group of community-based physiotherapists and occupational therapists not involved in the trial.

As discussed at the beginning of this chapter, the interpretive paradigm influenced the analysis of the process of domiciliary physiotherapy. The concepts of rigour and credibility (Krefting 1991) will be applied to judge the reliability and validity of the analysis. My role as researcher gave me the chance to be an observer of the DPS and, as manager, I was an accepted participant in the service. Participant observation as a research method (Atkinson and Hammersley 1994) has a good ‘fit’ with the interpretive paradigm (Nandhakumar 1997) as data are collected in the

natural setting. Although the a priori research design did not include formal participant observation, as the trial progressed I began to realise the value of my unique position. My experiences were rich in contextual integrity (Higgs and Titchen 1995, Parry 1997), and although it could be argued that different participant observers may have different interpretations of the same phenomena (Orme 1997), my in-depth exposure to the research context served to make me more sensitive to the issues around me, thus enhancing the credibility of my experiential knowledge (Streubert and Carpenter 1995). The credibility of the research may be judged in part simply by how well it deepens the readers' understanding of the phenomenon of domiciliary physiotherapy (Maykut and Morehouse 1994). In my position as manager I was able to overcome some of the barriers to understanding that come from researchers' using interview situations to gain knowledge about behaviours (Nandhakumar 1997). Verbal descriptions from interview respondents can lead to misinterpretations as the researcher cannot assume that they understand respondents descriptions of their behaviour specific to a particular context (Taylor and Bogdan 1985). Respondents may not accurately report what they do, or they may deliberately mislead the researcher if they do not want to disclose their behaviours (Van Maanen 1979). Alternatively, respondents may not be fully aware of their actions if they form part of everyday routines and therefore may be unable to give an account of them (Nandhakumar 1997).

The subjects (i.e. the clients) in the RCT at the centre of this PhD research were necessarily subject to control and assessment. In contrast, the participants in the study of the process of domiciliary physiotherapy were able to guide and influence the direction of the research. By providing detail about the sampling of participants, data gathering and analysis the reader may also judge the rigour of the research (Appleton 1995). For example, how transferable are the findings to other settings? Would the findings be consistent if the study were repeated?

Manipulating multiple data sources has enhanced the overall evaluation of domiciliary physiotherapy (Bryman 1988, Patton 1990) and these data have been used to inductively construct, rather than discover, the process of domiciliary physiotherapy (Strauss 1987, Patton 1990, Higgs and Titchen 1995). Sources of data used for the analysis of the process of domiciliary physiotherapy are discussed in more detail in the following sections.

6.4 SOURCES OF DATA RELATING TO EACH OBJECTIVE IN THE ANALYSIS OF THE PROCESS OF DOMICILIARY PHYSIOTHERAPY

6.4.1 GPs' diagnoses and reasons for client referral

Physiotherapy operates as a second-line service in most situations, with patients coming to physiotherapy after being referred by another professional, usually a doctor. Referral information forms the basis for the initial physiotherapy assessment, and diagnostic information is essential to the physiotherapist when devising treatment strategies. For example, a diagnosis of heart disease would alert the physiotherapist to the possible dangers to the patient of unaccustomed exercise or activity. A previous limb fracture, managed by internal metal fixation, would contra-indicate the use of most forms of electrotherapy. A diagnosis of osteoporosis would signal to the physiotherapist that the client might be at risk from fractures. When entering patients to the trial, GPs were required to fill in a referral form (see Appendix 3). The form was designed to provide physiotherapists with standard referral information, such as name, address, date of birth, diagnosis and current medication. To further investigate why GPs thought physiotherapy was appropriate, they were asked to write down their reason for referral. Qualitative data, in written form, was extracted from these forms to provide information on client diagnosis and reason for GP referral. On the whole, GPs were co-operative and filled in the form. For 205 clients (92% of those interviewed at stage 1) a referral form was submitted. The fieldworkers contacted all GPs who had not submitted referral forms, but the remaining 8% of forms were not received.

6.4.2 Quantitative analysis of number of physiotherapy visits and episodes of intervention

As previously discussed, data on number of visits, duration of each episode of treatment, and number of treatment episodes was used to provide a quantifiable profile of service provision. The physiotherapists determined how many treatment visits should be made and an episode of treatment ended when the physiotherapist discharged the client. No upper or lower limits were set for treatment sessions or visits. Instead the physiotherapists were able to determine the optimum number of treatments, frequency of visits, and when to discharge the client. Factors that may have influenced physiotherapists' decisions about when to end treatment are discussed in Chapter Five. Data on physiotherapy visits were obtained from physiotherapists' case notes. The DPS staff were regularly reminded to write up notes on a daily basis and not to rely on memory at a later date, in order to enhance the reliability and validity of the data.

6.4.3 Clients and carers perceptions of the role and value of domiciliary physiotherapy

An interactive relationship, which may be therapeutic in itself, often develops between client and therapist (Stone 1991) during physiotherapy. It was therefore important to evaluate domiciliary physiotherapy from the perspective of the client and carer (Parry 1991). According to a symbolic interactionist perspective (Blumer 1969), value was given to clients' and carers' interpretation of the meaning of their contact with the DPS. Two case studies of clients who had received regular domiciliary physiotherapy alongside other community-based services were selected in order to provide an insight into the user perspective on domiciliary physiotherapy. Purposive sampling was used to select the two cases (Silverman 1993). The DPS staff were asked to nominate two clients with knowledge and experience of domiciliary physiotherapy, who, therefore, had to be chosen from the experimental group. Control clients were not interviewed, as the purpose was to provide a user perspective on the experimental intervention only.

The small sample size inevitably limits the extent to which generalisations can be made from the data (Fetterman 1989). However the limited generalisability of qualitative research can be balanced by the high degree of relevance and credibility of information gained from purposive sampling, where respondents have been chosen for their knowledge and experience in a particular area. Semi-structured discussion interviews, involving the client, carer and researcher, were conducted in each of the client's homes. Each interview lasted approximately one hour. I introduced myself as a researcher, not a physiotherapist, in order to appear 'neutral' to the topic of discussion.

The interviews were structured around the following pre-determined broad topics:

- The role and function of the DPS and its impact on the client's level of independence and health status.
- The value of the DPS, in itself and as part of a wider primary health care team.

I decided to conduct the interviews myself, rather than use fieldworkers, as I wanted to hear first-hand the views and experiences of respondents. Moreover, my subject knowledge allowed me to pick up and explore any unanticipated channels of thought, as they emerged within the interviews (Silverman 1993). Respondents were not prevented from digressing, as allowing freedom to move off the point often leads to discovery of issues of central concern, not previously considered by the researcher (Measor 1985). It was hoped that by involving both the client and carer they would spark off ideas in each other and extend the depth of information gained. It was intended to audiotape and transcribe both interviews in order to enhance the reliability of data. However, in one case, the respondents did not want to be taped. The un-taped interview was therefore recorded by making detailed observational and theoretical notes (Schatzman and Strauss 1973). Hughes (1994) describes her use of observational and theoretical notes in a participant observational study of stepfamilies. She suggests that observational notes should be records of events experienced through watching or listening; and theoretical notes, which are deliberate attempts at deriving meaning from the observational

notes, should be made after the event. In practice, I found myself taking a more pragmatic approach, with observational and theoretical notes taken simultaneously both during the interview and immediately afterwards. In the un-taped interview, important comments may have escaped my notice. However, consistent interpretation of underlying meaning enhances the rigour of qualitative data more than verbatim recording of the actual words spoken (Kirk and Miller 1986). Data from the interviews provided a user perspective, which illuminated the quantitative outcomes of the trial and informed the interpretive analysis of domiciliary physiotherapy.

6.4.4 The views of experienced community-based therapists

A focus group discussion with experienced community based therapists unconnected to the DPS was conducted after the trial in order to broaden the understanding of the phenomenon of domiciliary physiotherapy. Group interviewing was developed in the 1950's, as a tool for market research (Merton *et al.* 1956), and is now gaining credibility in qualitative evaluation research (Patton 1990). The main advantage of group interviewing lies in it's efficiency. In one hour a researcher can get information from six people instead of one. Also, interaction within a group tends to expose both the extreme and the typical viewpoint (Bryman 1988, Patton 1990) which helps to reveal a more complete understanding of issues (Vaughn *et al.* 1996). A convenience sample of 6 therapists (3 occupational therapists and 3 physiotherapists) undertaking a part-time degree course at the author's workplace were invited to take part in a discussion about their practice. The group was conducted in a university classroom during a timetabled session and lasted for approximately 2 hours. It was audiotaped with the permission of the participants and later transcribed. We sat in a circle and I introduced myself as a lecturer/researcher and gave them a brief overview of the DPS trial. I said that as part of my PhD research I wanted to find out more about community-based domiciliary therapy practice. As in the client/carer interviews the style of the discussion was conversational and semi-structured. The aim of the focus group was to investigate the therapists' perceptions of

community-based therapy practice. Participants were asked to reflect on their past and present practice and themes covered in the discussion were as follows:

- Their early experiences as community-based practitioners.
- How they coped with difficult/challenging cases.
- Their view of themselves, now, as experienced community-based practitioners.

I encouraged discussion among participants and tried as far as possible to take a minimal role in conversation. However, I did use my knowledge as an experienced therapist to steer discussion along relevant avenues. My insider perspective (Reed 1995) gave added sensitivity to the collection and interpretation of information gained.

6.4.5 Reflexive analysis

My part in the organisation, management and research of the DPS was retrospectively regarded as in-depth participant observation. Data were inductively derived (Fetterman 1989) in the form of notes, thoughts and reflections on the following situations:

- Observation of critical events, such as conflict over whether or not staff should wear uniform.
- Participation in meetings, where staff presented case histories of their clients.
- Acting as mentor to staff in the early stages of their 'career' in domiciliary physiotherapy.
- Accompanying staff on visits, where a second opinion was required.

It was only after the trial that I began to mentally organise my thoughts on the process of domiciliary physiotherapy and reflect on and interpret their meaning. Self-reflective enquiry of this kind may be considered a personal activity, and in the positivist paradigm would be viewed as biased and unreliable. However, interpretive philosophy embraces reflexivity as an integral part of research. Titchen and Higgs (1995) suggest that by systematically reflecting on experiences and theorising from practice, knowledge can be generated which others can test. In the field of nursing, critical reflective inquiry is now viewed as an essential methodology to develop knowledge for improving practice (Hesook 1999). Schon (1991) also acknowledges the

reflection-on-action that professionals engage in to improve and extend their practice.

Reflexivity and reflection are essential in action research when individuals or groups are initiating and evaluating change (McTaggart 1993). Although generalisation beyond the immediate context may not be appropriate, the knowledge generated through reflection may provide insights into practice and offer a basis for further planned enquiry.

6.5 ANALYSIS OF DATA

Data obtained from client/carer interviews and from the focus group discussion were integrated with my personal and experiential knowledge to construct an interpretive account of the process of domiciliary physiotherapy. A model of domiciliary physiotherapy was then developed to visualise the interactions between physiotherapist, client and carer. An interpretive account takes into consideration multiple perspectives to explain the meaning of sequences of events and patterns of behaviour (Stringer 1996). In an interpretive paradigm, data collection and data analysis are interdependent (Jensen 1989, Patton 1990, Silverman 1993). Each data source was considered deductively, with questions or themes in mind, and inductively, with no preconceived ideas about what the data would reveal. Qualitative data from the interviews and the focus group were analysed using techniques 'borrowed' from the grounded theory method (Strauss and Corbin 1990), although it must be stressed that the analysis of the process of domiciliary physiotherapy does not constitute a fully developed 'grounded theory'.

Practical instructions given in Turner (1981), Corbin (1986), Strauss (1987) and Stringer (1996) were used to structure the data analysis, as outlined in points 1-5 below:

- 1) Data were broken down into themes (abstractions of phenomena observed in the data).

Firstly, data were analysed in a deductive manner, in the light of the experimental hypotheses.

From the client and carer interviews, a theme of the role of domiciliary physiotherapy in improving clients' level of independence emerged. Secondly, data were analysed in an

inductive manner, using experiential knowledge to ask analytical questions of the data. A theme

of providing emotional support for clients and carers emerged, from the client/carer interviews, as part of the process of domiciliary physiotherapy.

2) Categories within themes were identified. For example, within the theme of emotional support for clients and carers, categories of counselling and giving faith and reassurance were identified.

3) Categories were reviewed and, where necessary, revised through a process of theoretical reflection. For example, the relationship between the client and the physiotherapist emerged as a category under the theme of the role of domiciliary physiotherapy in improving clients' level of health. Although the client-therapist relationship could contribute to emotional support, the data from the interviews were interpreted to mean the relationship was a therapeutic one, which improved clients' mood and level of confidence. In my experience, using a therapeutic relationship to instil confidence is quite different to developing a good relationship in order to counsel and reassure.

4) Client and therapist perspectives were juxtaposed within categories. For example, under the theme of having the service provided at home, categories of values and benefits and drawbacks emerged. Although one carer greatly valued the services her husband had received, she found the presence of 'strangers' in her home stressful. Therapists were not necessarily aware that their input could provoke stress in carers.

5) The interpretive analysis of the process of domiciliary physiotherapy was constructed by integrating data sources from clients, carers, experienced therapists and myself, checking to see if concepts or theories emerging from one data source were corroborated in another, and juxtaposing one perspective against another.

The relationship between the researcher and the research setting requires special consideration when considering issues of rigour and credibility. In qualitative research, the researcher is the 'instrument' (Patton 1990), interacting and participating within the research setting when collecting data. Strauss (1987) dismisses the criticism of some authors (Bryman 1988), that participation introduces bias, by claiming that experiential data give added theoretical sensitivity, from which a more credible interpretation can be constructed. The rigour of qualitative research depends on a consistency of interpretation on the part of the researcher, not just on whether or not spoken words have been taped or written down (Kirk and Miller 1986). No one can make the pretence of being a neutral observer, and many authors would argue that quantitative researchers make false claims to objectivity (Silverman 1993, Ely *et al.* 1994, Miles and Huberman 1994). Empathy and closeness with programme participants must be achieved before understanding can develop (Strauss 1987, Patton 1990).

7. SUMMARY

This chapter has given an account of the methods of an in-depth evaluation of domiciliary physiotherapy. The author's own 'paradigm shift' has been discussed and positivist and interpretivist paradigms have been brought together to underpin an investigation that focuses mainly on outcomes but acknowledges the importance of process. Traditional experimental methods in the form of an RCT were selected for the main part of the research, which aimed to assess the cost effectiveness of domiciliary physiotherapy. The advantages and disadvantages of the RCT have been considered, although further in-depth critique of the research methodology will come later in the thesis. An emerging reflexive approach has been presented, where multiple data sources have been amalgamated to construct an interpretive account of the process of domiciliary physiotherapy. The interpretive account has been used to underpin a model of domiciliary physiotherapy, which is presented later in the thesis. The following chapters will present the research results and findings, beginning with the results of the RCT and going on to the interpretive analysis and model of domiciliary physiotherapy. In the final

discussion chapter, the overall research will be critically reviewed in terms of strengths and weaknesses and implications for the theory and practice of domiciliary physiotherapy.

CHAPTER THREE

RESULTS OF THE RANDOMISED CONTROLLED TRIAL

PART ONE: SAMPLE CHARACTERISTICS, REPRESENTATIVENESS AND ATTRITION

1. OVERVIEW OF THE CHAPTER

This chapter examines the sample recruited to the RCT, and forms a preface to the next chapter (Chapter Four) in which the outcomes of the trial will be presented. Firstly, the sample recruited to the trial will be described in terms of selected social, demographic and clinical parameters. Next, the external validity of the trial will be examined through a comparison of the trial sample with a 'post-trial sample' of the first 85 clients referred to the service at the end of randomisation, and of the trial sample with samples referred to other services in the UK. The extent to which changes on the dependent measure may be due to the experimental intervention depends as much on comparability of groups being maintained throughout the course of a trial, as it does on comparability of groups at the start (Cook and Campbell 1979). Therefore the internal validity of the trial will be assessed not only by statistically comparing the baseline characteristics of the initial experimental and control groups but also by analysing the effects of sample attrition on comparability of groups. At the end of the chapter the effects of sample attrition on both internal and external validity will be summarised.

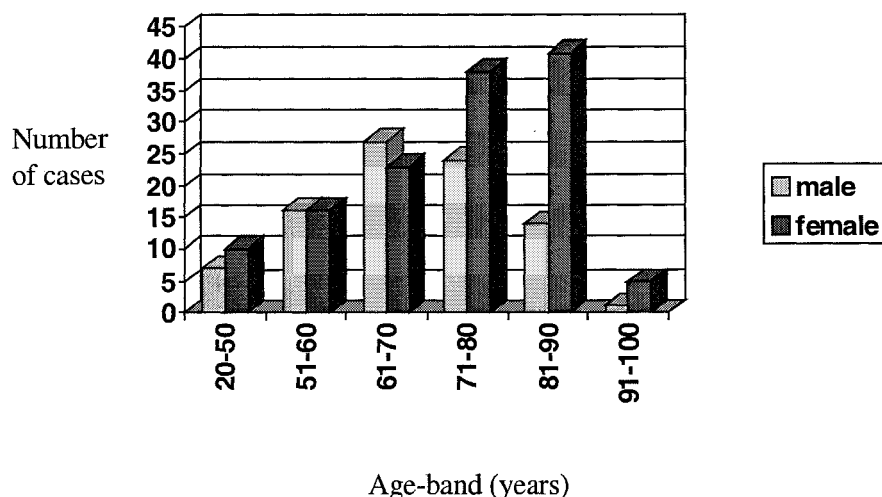
2. CHARACTERISTICS OF THE SAMPLE

A total of 245 clients were referred to the trial, but 9 (7%) of the experimental group and 14 (11%) of the control group (making a total of 23 (9%) of the entire sample) were not interviewed at the first stage, either because they refused or were too ill. Baseline data were therefore collected on 222 clients (114 experimental and 108 control). The characteristics of the sample will be described in terms of age, gender, diagnosis, level of independence, health status, social circumstances and carer support.

2.1 AGE-GENDER DISTRIBUTION

Figure 2

Bar chart to show baseline age-band by gender of clients referred to the trial (n=222)



The above bar chart shows the number of male and female clients in age-bands ranging from 20-100 years. Ages of clients ranged from a minimum of 24 years to a maximum of 94 years. The distribution was skewed very much towards the older age ranges, with 183 clients (78%) over 60 years old and 123 (56%) older than 70 years. The median age was 73 years (IQR = 19). In the younger age groups, there were fairly equal proportions of men and women, whereas among clients aged over 70 years, 68% were women and only 32% were men. Overall there were more women than men, in the ratio of 3:2.

2.2 DIAGNOSIS

Referring GPs provided at least one diagnosis for 205 (92%) of the 222 cases. In the remaining 8% of cases, GPs either did not fill in a referral form or left the diagnosis section blank. The primary or main diagnosis was initially classified according to the International Classification of Diseases (World Health Organization 1977), and then re-coded into four main diagnostic groups to represent groupings of conditions commonly referred to physiotherapy: *neurological problems* (e.g. stroke, multiple sclerosis, Parkinson's disease, motor neurone disease),

orthopaedic/rheumatological problems (e.g. rheumatoid arthritis, osteoarthritis, fractures),
respiratory problems (e.g. chronic obstructive airways disease, bronchiectasis, lung cancer) and
other problems (e.g. heart/vascular disease, non-specific mobility problems and skin ulcers).

Table 3 shows the proportions of clients in each diagnostic group.

Table 3 Baseline primary diagnostic groups of clients referred to the trial (n=205)

Diagnosis	n (%)
Neurological	77 (38%)
Orthopaedic/rheumatological	65 (32%)
Respiratory	50 (24%)
Other	13 (6%)
Total	205 (100%)

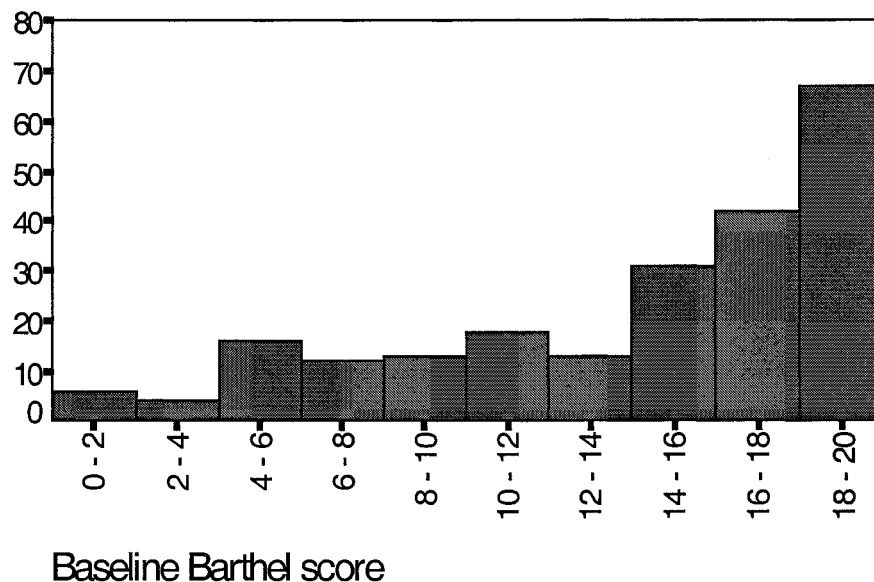
Clients with neurological or orthopaedic/rheumatological problems together made up 70% of the sample. The remaining 30% were mainly clients with a primary respiratory diagnosis.

2.3 INDEPENDENCE IN ACTIVITIES OF DAILY LIVING

Independence was measured using clients' self-reported performance on the Barthel Activities of Daily Living Index. Figure 3 overleaf shows baseline Barthel scores for all 222 clients interviewed at the first stage.

Figure 3 Histogram of baseline Barthel Index scores of total sample of clients referred to the trial (n=222)

Number of
cases



Scores ranged from 0 to 20, with the distribution skewed towards the top of the scale. The median score was 15 (IQR = 8), and 75% of the sample had an initial Barthel score of 10 or more. According to Wade and Langton Hewer (1987), scores of 10-14 on the Barthel indicate moderate disability and scores of 15-19 indicate mild disability. Therefore, the majority of clients referred to the trial were only mildly disabled as measured by the Barthel Index. However, clients had to be unable to travel to outpatient physiotherapy to enter the trial, which casts some doubt on the ability of the Barthel Index to measure the disability of the client group. Summed scores can give no more than a crude indication of disability, and the sensitivity of the Barthel Index will be discussed further in Chapter Four.

2.4 HEALTH STATUS

Part one of the Nottingham Health Profile (NHP) was used to measure health status in six areas: energy, pain, emotions, sleep, social isolation and physical mobility. Respondents tick yes/no, on a self-administered questionnaire, to a number of weighted statements for each area. The

weightings reflect the relative importance of each statement (Hunt *et al.* 1989). The potential weighted score for each area can fall on a number of incremental points between 0 and 100, 0 indicating good health status and 100 very poor health status as measured by the profile. The effect of the weighted scores on analysis of data will be further discussed in Chapter 4. Baseline NHP scores, for each area, were not available in all 222 cases in the initial sample. Data were missing when clients omitted one or more statements in the profile. Table 4 below shows the median and inter-quartile ranges for scores in each area and the number of cases for which scores were obtained.

Table 4 Medians and inter-quartile ranges of baseline Nottingham Health Profile Scores (n=198-200)

	Energy n=200	Pain n=198	Emotions n=198	Sleep n=198	Social n=198	Physical mobility n=199
Median score	60.8	28.7	26.6	38.5	22.0	54.6
25th-75th percentiles	24-100	6-69	7-53	13-78	0-42	31-68
(Inter-quartile range)	(76)	(63)	(46)	(65)	(42)	(37)

In the areas of energy, sleep and physical mobility the median scores were greater than 30, indicating severe distress as measured by the profile (Ebrahim *et al.* 1986). For pain, emotions and social isolation, the median scores were not in the severe distress category, but were higher than age weighted norms (Hunt *et al.* 1989). Clients referred to the trial were, by definition, suffering from physical disability and were possibly confined to the house. Therefore, low levels of perceived health status could be expected. It should be noted that the relatively high scores on the Barthel Index do not match up with the severe distress scores on the physical mobility area of the NHP, perhaps reinforcing the point made in the previous sub-section that

the Barthel may not have been a sensitive measure. The advantages and disadvantages of both the Barthel and the NHP will be further discussed in Chapter Four.

2.5 COMMUNICATION

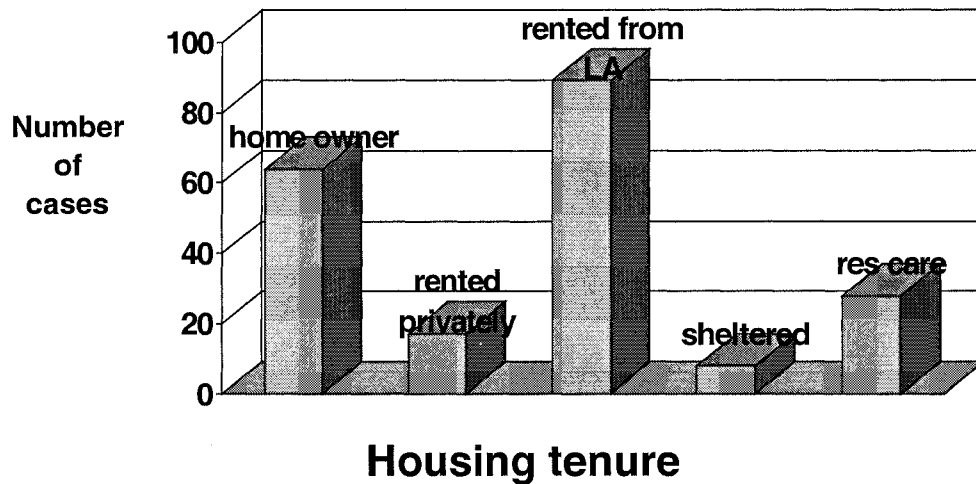
It was not the intention of this study to assess expressive or receptive speech and language problems. However, the fieldworker made a simple subjective judgement of clients' communication. If the fieldworker experienced difficulty in communicating with the client, e.g. due to dysphasia, they noted that the client had a communication problem. Problems such as deafness or slowness of speech were not noted, provided they did not compromise the interview. Fieldworkers noted that 49 clients (22%) had a communication problem. In 27 of these cases (55%) the carer interpreted or answered for the client. Half of the clients with a communication problem were men (n=25) and half were women (n=24). Diagnosis was known in 44 out of the 49 communication impaired cases: 32 had a neurological condition, 7 had rheumatoid/osteoarthritis or a fracture, 4 had a respiratory condition and 1 had a heart problem. Of those with a communication problem, 40 (82%) were over 60 years old.

2.6 SOCIAL STATUS

It was anticipated that the sample would consist of mainly elderly females. Therefore the usual method of measuring social class, based on husband's last occupation, was unlikely to provide a meaningful classification (Marsh 1986). Instead, housing tenure was used as an indicator of social status. In a longitudinal study of socio-demographic mortality differentials, Fox and Goldblatt (1982) used three housing sub-groups for classification: owner-occupied, privately rented and local authority rented. They found these sub-groups to be useful social indicators and powerful discriminators of mortality. At the time of the trial, the most recent literature suggested that home owning was indicative of a higher social class than renting, and renting privately indicated higher social status than renting from the local authority (Fox and Goldblatt 1982). More current literature confirms that home owning remains an important indicator of higher social class (DiSalvo and Ermish 1997).

Figure 4

Bar chart to show baseline housing tenure of clients referred to the trial (n=206)



Information on housing tenure was not given by 16 clients. Figure 4 above shows that in the sample of 206 where housing tenure was known 64 (31%) owned their own home, 17 (8%) rented privately, 89 (43%) rented their home from the local authority, 8 (4%) were in sheltered accommodation and 28 (14%) were in residential care. Of those in residential care, 10 lived in social services homes and 18 lived in private homes. A high proportion (61%) of the sample were in local authority rented accommodation (either houses or residential/sheltered accommodation), indicating that a majority of clients were from 'lower' social classes. Of the homeowners (n=64), 40 (63%) were female. Similarly, 61 (58%) of the 106 clients in rented accommodation were also female.

2.7 SOCIAL SUPPORT

Of the 222 clients referred to the trial, 67 (30%) lived alone at home. Of those living alone, 49 (73%) were women and 48 (72%) were aged over 70 years. Ten clients received formal care attendant support from agencies such as the Leonard Cheshire Foundation and local voluntary groups. The frequency of care ranged from less than once per week to daily, seven days per week. Home help input, provided mainly by social services, was received by 64 clients (29%).

The majority of these clients received help once or twice per week, although 2 clients received home help support seven days per week. A total of 88 clients (40%) said they had an informal carer who helped them on a regular basis with personal tasks. Of these 88 clients, 60 (68%) were aged over 60 years and 48 (54%) were male. The burdens of caring fell largely to women, as 65 (74%) of carers were female, and the majority of carers (89%) lived with the client they were caring for. Williams and Fitton (1991) found a similar pattern in their study of carers of elderly patients discharged from hospital, with 67% of carers being women, and 33% men. Of the 88 clients who reported having a carer, most said their spouse provided care. Other carers were reported as children, other relatives or friends, as shown in Table 5 below.

Table 5 Carers' relationship to client, as reported by clients at baseline (n=88)

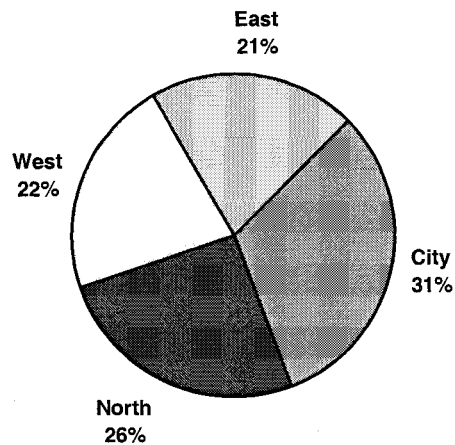
Carers' relationship to client	n(%)
Spouse	49(56%)
Child	19(21%)
Other relative	14(16%)
Friend	6(7%)
Total	88(100%)

2.8 AREA OF RESIDENCE

At the time of the trial, Newcastle Community Health Services divided the city into four geographical areas for the purpose of delivering care: City (the inner-city area), North, West and East. The DPS team used these areas to organise service delivery. Figure 5 overleaf shows the percentages of clients living in each of the four areas. There were 70 clients (31%) in the City area, 57 clients (26%) in the North area, 49 clients (22%) in the West area and 46 clients (21%) in the East area. Although there were slightly more referrals in the City area, all areas of Newcastle were well represented in the trial.

Figure 5

Pie chart to show allocation of clients to area physiotherapy teams (n=222)



3. EXTERNAL VALIDITY: SAMPLE REPRESENTATIVENESS

In this section the external validity of the trial will be addressed by examining whether or not the sample recruited to the trial was representative of target populations. Firstly, the trial sample will be compared with a post-trial sample of the first 85 clients referred after randomisation ended, in order to see if the trial recruited the same types of clients referred to an open domiciliary physiotherapy service in Newcastle. Secondly, selected literature on domiciliary physiotherapy services will be used to determine the characteristics of clients referred in other parts of the UK. The characteristics of clients referred to other services will be compared with those of clients referred to the trial, in order to see if the trial recruited the same types of clients referred to services across the UK.

3.1 COMPARISON OF TRIAL AND POST-TRIAL SAMPLES

The unexpected poor rate of recruitment previously discussed in Chapter Two (Methods) raised concerns about whether or not GPs were withholding certain 'types' of client from the trial. After recruitment to the trial ended, the DPS was retained as part of Newcastle Community

Services and, for a limited time, fieldworkers interviewed new referrals to obtain the same baseline data as had been obtained from the trial clients. The trial sample has been compared, on a range of characteristics, with a 'post-trial sample' of the first 85 clients referred to the service at the end of randomisation, in order to assess the external validity of the trial, i.e. whether the sample referred to the RCT was representative of clients who would usually be referred to a domiciliary physiotherapy service in Newcastle. Table 8.1. (Appendix 8) compares key baseline social/demographic and health/disability characteristics of clients referred to the trial with those of clients referred after randomisation ended. Appropriate parametric and non-parametric tests were used to check whether the groups were comparable within statistical limits. A probability level of 0.05 was chosen as the critical value above which any differences were not significant. As recommended by Altman (1991), the actual p value, rounded to 2 decimal places, is stated in all tables.

The post-trial sample was found to be comparable, within statistical limits, to the sample referred to the trial, on all but two variables. Firstly, there was a significantly higher proportion of clients in the post-trial group with communication problems (chi-square $p=0.01$). Secondly, there was a significant difference between the two samples in relation to clients' primary diagnosis. The trial sample had greater proportions of clients with 'neurological' and 'other' problems (chi-square $p=0.02$). It seems that GPs may have withheld some clients with communication problems from the trial. Perhaps the difficulty in obtaining informed consent was a barrier to recruitment. Communication-impaired clients could have been excluded from the outset but, in keeping with the requirement for heterogeneous sampling in pragmatic trials, minimal exclusion criteria were specified. Proportionately fewer clients with neurological problems and more clients with 'other' diagnoses were referred after the trial. The nature of 'other' diagnoses is varied and may not be a reliable category for comparison. It should be noted that if the 'other' category is excluded from the comparison of diagnoses the chi-square p value becomes non-significant, indicating that the significant difference may be an artifact

rather than a valid result. Alternatively, perhaps recruitment to the trial used up an existing 'pool' of neurological clients, leaving fewer clients to be referred after the trial.

3.2 COMPARISON OF TRIAL SAMPLE WITH POPULATIONS REFERRED TO OTHER SERVICES

As discussed in Chapter One, domiciliary physiotherapy schemes have been shown to vary, in that they may have 'open' referral policies, or they may be highly selective and accept only patients with a particular diagnosis, e.g. stroke. Three selected reports on domiciliary physiotherapy services that did not restrict referrals to one diagnostic group of patients (Frazer 1980, Sheffield Health Authority 1982, Smyth 1985) have been reviewed, for the purpose of comparing the trial sample with populations referred to other services. It has been assumed that the three selected services are representative of services across the UK. Frazer (1980) described a sample of 400 patients referred to a new domiciliary physiotherapy service in Birmingham; Sheffield Health Authority (SHA) (1982) produced a public report on a pilot scheme of community physiotherapy, to which 2422 patients were referred over 2 years; and Smyth (1985) surveyed 208 patients seen by a community physiotherapist in Norwich in one year. Table 6 shows a comparison of client characteristics reported in these papers with characteristics of clients referred to the DPS trial.

Table 6 Comparison of characteristics of clients referred to other services with those referred to the trial of domiciliary physiotherapy

Characteristics for comparison	Frazer (1980)	SHA (1982)	Smyth (1985)	DPS trial
<i>Aged over 60/65 years</i>	91.5%	92%	79%	78%
<i>Aged over 70 years</i>	77%	72%	not given	56%
<i>Female</i>	68%	65%	not given	60%
<i>Male</i>	32%	35%	not given	40%
<i>Neurological diagnosis</i>	35%	23%	Diagnostic statistics not given, but similar conditions reported.	38%
<i>Orthopaedic/</i>				
<i>rheumatological diagnosis</i>	42%	47%		32%
<i>Respiratory diagnosis</i>	5%	21%		24%

Frazer (1980) reported that 91.5% of referrals were for people aged 65 and over, and 77% for the over 70s. Similarly, 92% of referrals to Sheffield Health Authority's scheme were for the over 60s, and 72% were for people aged 70 and over (SHA 1982). Smyth (1985) did not provide a detailed age profile, but reported that 79% of referrals were for people aged over 65 years. Although these percentages are higher than the 78% of referrals for those aged 60 and over and the 56% for the over 70s in the DPS trial, the comparisons show that the majority of referrals to domiciliary physiotherapy services are likely to be for the elderly. It should be noted that Frazer and Sheffield Health Authority both targeted the elderly population in their service provision, where the Newcastle DPS did not. Frazer (1980) reported that 68% of total referrals were for women and 32% for men. The majority of Sheffield Health Authority's referrals were also for women. Smyth did not give details of gender of referrals. The ratios of women to men reported by Frazer and Sheffield Health Authority correlate well with the 60:40 ratio of women to men referred to the Newcastle DPS. The diagnoses of clients referred to the Newcastle DPS

were grouped into neurological, orthopaedic/rheumatological, respiratory and 'other' categories. Frazer, Sheffield Health Authority and Smyth all give some indication of diagnostic groupings. The categories are not consistent throughout the studies, making comparisons difficult. However, by reanalysing data given in the reports, it is possible to estimate that Frazer reported 35% neurological referrals, 42% orthopaedic/rheumatological referrals and 5% respiratory referrals, and Sheffield Health Authority reported 23% neurological referrals, 47% orthopaedic/rheumatological referrals and 21% respiratory referrals. Except for the low percentage of respiratory referrals reported by Frazer, these percentages correlate quite well with the 38% neurological, 32% orthopaedic/rheumatological and 24% respiratory referrals to the Newcastle DPS. Smyth did not give numbers of patients in different diagnostic categories, but listed a range of 'common conditions' referred which were similar to those referred to the Newcastle DPS. Therefore from information given in three selected descriptive reports it seems that, on a limited set of indicators, the sample of clients referred to the Newcastle DPS was broadly representative of those referred to other domiciliary/community physiotherapy services. Since the trial, a survey of community-based physiotherapy in the Trent Region (Seymour and Kerr 1996) has shown that stroke and other neurological problems, mobility/general problems of the elderly, rheumatological conditions and orthopaedics still figure among the main diagnostic conditions referred to domiciliary physiotherapists. The Trent survey also showed that the majority of patients referred continue to be older (over 50 years), although males and females were referred in more equal numbers than in the studies cited from the 1980s. It seems reasonable to assume that, despite the time period since the DPS trial, the results, conclusions and recommendations of this research are relevant to contemporary domiciliary physiotherapy services.

3.3 SUMMARY OF ANALYSIS OF SAMPLE REPRESENTATIVENESS

The post-trial sample was slightly different from the trial sample, in that it consisted of proportionately more clients with communication problems and less clients with neurological

conditions. However, these differences have been explained and they are not sufficient to cast serious doubt upon the validity of generalising from the results of the trial to an established DPS in Newcastle. As far as can be assessed, it would seem that the sample referred to the trial was representative, on selected indicators, of populations likely to be referred to other services in the UK. In summary, the sample recruited to the trial has been shown to be largely representative of the target population.

4. INTERNAL VALIDITY: BASELINE COMPARABILITY OF EXPERIMENTAL AND CONTROL GROUPS AND THE EFFECT OF SAMPLE ATTRITION

Experimental and control groups were formed by a process of random allocation, to ensure that changes on the dependent measures were due to the experimental intervention, and not any other uncontrolled variables (Cook and Campbell 1979, Altman 1991, Pollock *et al.* 1993). However, not all threats to internal validity can be accounted for by random allocation (Cook and Campbell 1979). This section will discuss the internal validity of the trial by addressing a series of questions, as shown below:

- *Was random allocation successful in creating two initially comparable groups?*
- *Was the rate of and reason for sample attrition the same for both groups?*
- *What were the characteristics of dropouts and did they differ from those who stayed in the trial?*
- *Did sample attrition effect the comparability of the groups still remaining at the final interview?*

4.1 WAS RANDOM ALLOCATION SUCCESSFUL IN CREATING TWO INITIALLY COMPARABLE GROUPS?

Table 8.2. (Appendix 8) compares key baseline social/demographic and health/disability characteristics of clients initially randomised to the experimental and control groups. The following comparison variables were measured: age, gender, primary diagnosis, Barthel score, NHP score, communication impairment, whether the client lived alone, housing tenure (as a measure of social status), presence of an informal carer and allocation to DPS area physiotherapy teams. Appropriate parametric and non-parametric tests were used to assess whether the groups were comparable within statistical limits. For most variables, baseline data were available for 114 (93%) experimental and 108 (89%) control clients. Occasionally the number of cases for which data were available was reduced, due to inability/unwillingness of clients to comply with various parts of the interview schedule. There were no significant differences between the experimental and control groups on any of the selected variables, demonstrating that (within the limits of statistical testing) random allocation was successful in creating two initially comparable groups.

4.2 WAS THE RATE OF AND REASON FOR SAMPLE ATTRITION THE SAME FOR BOTH GROUPS?

Sample attrition poses a serious threat to internal validity, because any observed effect of the experimental intervention could be due to sample bias created by subjects dropping out of the study (Cook and Campbell 1979). A total of 245 clients consented to take part and were recruited to the trial, of whom 23 (9 experimental, 14 control) were not interviewed at the first stage. Reliable data are not available on the reasons for these unexpected early 'drop outs'. Some control clients who refused the first interview seemed to have not fully understood the implications of participating in the study, believing that all participants would receive domiciliary physiotherapy. Others in both groups said they were too ill. Baseline data were therefore available for an initial sample of 222 clients. At later stages in the study, reasons for drop out were systematically recorded. There was a loss of subjects due to death, refusal to be

interviewed, clients moving away, or illness. It should be noted that no clients refused the intervention (i.e. domiciliary physiotherapy). When clients refused to be interviewed they continued to receive treatment from the DPS.

Table 7 illustrates sample attrition rates by showing the number and percentage of experimental and control clients interviewed at each of the three stages. Figures for the table have been derived from counting the number of subjects for whom Barthel Index scores were available (Barthel scores were successfully obtained from all patients available for interview at each stage). For other outcome measures, e.g. items of the Nottingham Health Profile, fewer data were available, due to clients selectively omitting individual statements in the profile.

Table 7 Sample attrition rates for experimental and control groups at 1st, 2nd and 3rd interview stages

	n of clients interviewed (% of n recruited) in experimental group [n=123]	n of clients interviewed (% of n recruited) in control group [n=122]	Total [n=245]
1st interview (within 1 week of referral)	114 (93%)	108 (89%)	222 (91%)
2nd interview (end of treatment or 12 weeks after referral)	103 (84%)	92 (75%)	195 (80%)
3rd interview (12 months after referral)	87 (71%)	75 (62%)	162 (66%)

chi-square=2.34, p=0.13

Overall, 91% of subjects recruited to the study were interviewed at the first stage, 80% were interviewed at the second stage and 66% were interviewed at the third stage. Therefore, by the

final 12 month interview, there had been a total of 34% sample attrition. At the first and second stages a high percentage of subjects in both the experimental and control groups were interviewed. However at the 3rd stage only 75 (62%) of the control subjects and 87 (71%) of the experimental subjects were interviewed. Although overall sample attrition was higher in the control group (38%) compared with the experimental group (29%), the difference was not statistically significant.

The most common reason for clients to be lost to the trial was death. A total of 17 clients (9 experimental and 8 control) died before the 2nd interview, and a further 18 died before the 3rd interview (11 experimental and 7 control). Other reasons for attrition were that clients had moved away (5 experimental and 4 control), or the client was too ill (1 control), or clients refused to be interviewed (2 experimental and 13 control). Refusal rates were markedly different in the experimental and control groups. Table 8 below shows the number and percentage of clients who refused to be interviewed (at any point after the 1st stage) cross-tabulated against the number and percentage who did not refuse, for the experimental and control groups.

Table 8 Refusals against non-refusals at any stage after the first interview by experimental and control groups

	Refused to be interviewed at either 2nd or 3rd stage n=15	Did not refuse to be interviewed at any stage n=162
Experimental group	2 (13%)	87 (54%)
Control group	13 (87%)	75 (46%)
Total	15 (100%)	162 (100%)

chi-square =8.95, p=0.003

The main reason for refusal to be interviewed, given by members of the control group, was their frustrations at not receiving any new health or social services provision. Table 8 shows that, by the final interview stage, a significantly higher proportion of 'refusers' were in the control group than the experimental group ($p=0.003$). The implication of this difference between groups is discussed in the final section of this chapter.

4.3 WHAT WERE THE CHARACTERISTICS OF DROPOUTS AND DID THEY DIFFER FROM THOSE WHO STAYED IN THE TRIAL?

A range of selected baseline variables was chosen to compare those who dropped out/were lost from the trial (for any reason), with those who were interviewed. Tables 8.3-8.8 (Appendix 8) show comparisons for the whole sample and then for the experimental and control groups separately, at both the 2nd and 3rd stages. Overall, clients who dropped out/were lost from the trial at the 2nd interview stage were significantly worse than those who remained, with respect to their baseline Barthel score ($p=0.004$) and their baseline score on the social isolation item of the NHP ($p=0.0005$). At the 3rd interview stage, those who were lost to the trial still scored significantly less on the baseline Barthel ($p=0.02$) and were significantly more socially isolated at baseline ($p=0.003$). They also had poorer baseline physical mobility ($p=0.005$) as measured by the NHP. Separate analyses for experimental and control groups of the differences between dropouts and those who remained showed very similar trends to the whole sample analysis. Possible reasons for the loss of the 'worst' clients are considered at the end of this chapter.

4.4 DID SAMPLE ATTRITION EFFECT THE COMPARABILITY OF THE GROUPS STILL REMAINING AT THE FINAL INTERVIEW?

Table 8.9 (Appendix 8) compares key baseline social/demographic and health/disability characteristics of experimental and control group clients who remained in the study for all three interviews. These comparisons give the best available estimate of the magnitude of any effect of sample attrition on the comparability of experimental and control groups remaining in the trial until the end. For most variables, comparison data were available for 87 (71%) experimental and 75 (61%) control clients. For some variables, the number of cases for which

data were available was reduced, due to inability/unwillingness of clients to comply with various parts of the interview schedule. The comparison variables are the same as those used for the comparison of the initial randomised groups, i.e. age, gender, primary diagnosis, Barthel score, NHP score, communication, living alone, housing tenure, informal carer and allocation to DPS area physiotherapy team. Again, appropriate tests have been used to assess whether the groups were comparable within statistical limits. There were no significant differences, on selected baseline characteristics, between experimental and control groups who remained in the study for all three interviews. Therefore, as far as can be assessed by statistical testing, sample attrition did not alter the comparability of the two groups.

5. IMPLICATIONS OF SAMPLE ATTRITION FOR THE RCT

Sample attrition can threaten both the internal and external validity of a trial, by limiting the extent to which any differences in outcome between the two groups can be truly attributed to the experimental intervention, and by restricting how far results can be generalised beyond the trial. In this trial of domiciliary physiotherapy, both the experimental and control groups suffered sample attrition. The difference between the two groups in magnitude of attrition rates (38% in the control group and 29% in the experimental group) was not statistically significant, thereby reducing the threat to internal validity. However, although there was no statistically significant difference in total sample attrition, the difference between the two groups in *refusal* rates was significant. After the first interview, there was 15% refusal in the control group, compared with 2% in the experimental group. High drop out rates in control groups are not unusual, and are difficult to prevent in studies where control subjects perceive they are receiving less than desirable treatment (Cook and Campbell 1979). Naturally, individuals want to receive the best treatment, and although control group clients did not refuse control *treatment*, some showed their resentment by dropping out of the interview schedule. Although a comparison of baseline characteristics of the experimental and control clients who were still in

the trial at the final stage showed no significant differences, unknown sample bias may have been created by the higher rate of control group refusals.

In general, clients in both groups who dropped out/were lost to the trial were more dependent in ADL and were more socially isolated than those who remained. Attrition of the more dependent, socially isolated clients may have biased the sample in terms of the external validity of results. Any conclusions drawn from the results may be only truly generalisable to a population with better health status than that likely to be referred to an established service. The problem of potential sample bias is not unique to this trial of domiciliary physiotherapy. Other studies involving elderly people have also found non-respondents to be more likely to experience ill health than respondents (Milne *et al.* 1971, Rockwood *et al.* 1989). Non-response and sample attrition is a common problem in research, and in the elderly age group the most vulnerable subjects are likely to be lost. However, random allocation with systematic attrition is still likely to yield a better sample than initial systematic assignment of carefully selected subjects to groups (Pollock *et al.* 1993, Cook and Campbell 1979).

6. SUMMARY OF THE CHAPTER

This chapter has examined the characteristics of the sample, and the internal and external validity of the trial has been assessed by analysing sample attrition and representativeness. The next chapter will present the main results of the trial, taking into consideration the implications of sample attrition discussed above.

CHAPTER FOUR

RESULTS OF THE RANDOMISED CONTROLLED TRIAL

PART TWO: THE COST EFFECTIVENESS OF DOMICILIARY PHYSIOTHERAPY

1. OVERVIEW OF THE CHAPTER

This chapter will present results relating to the cost effectiveness of introducing the DPS. As previously discussed in Chapter Two, the concept, rather than the technical model, of cost effectiveness was applied. The Barthel Index and Nottingham Health Profile results provide an assessment of effectiveness, and the analysis of clients' use of other services provides an estimate of the costs of introducing the new DPS against the cost of the DPS itself. Barthel Index and Nottingham Health Profile scores at initial referral, 3 months and 12 months will be analysed in this chapter. Client held diary data on cumulative use of other services over a period of up to 18 months will also be evaluated. The following experimental hypotheses will be tested:

- Domiciliary Physiotherapy will improve level of independence as measured by the Barthel Activities of Daily Living Index.
- Domiciliary Physiotherapy will improve health status as measured by the Nottingham Health Profile.
- Domiciliary Physiotherapy will reduce use of other health and social services.
- Domiciliary Physiotherapy will reduce the number of GP referrals.
- Domiciliary Physiotherapy will reduce the number of episodes of respite care and mean length of respite care stay.
- Domiciliary Physiotherapy will reduce the number of hospital admissions and mean length of hospital stay.

2. METHOD OF ANALYSIS OF RESULTS

2.1 METHOD OF ANALYSIS OF BARTHEL INDEX RESULTS

Independence in activities of daily living was measured using clients' self-reported performance on The Barthel Index. Although the total Barthel score is widely used as an outcome measure in both clinical practice and research, there is no standard convention of how many points increase or decrease constitute a meaningful change over time on the scale. Users of the Barthel, seeking guidance on how to interpret a change in score, will be frustrated by the conflict of opinion that exists in the literature. Collin *et al.* (1988) expressed the view that score differences of 3 points were needed for a 'probably genuine' change and differences of 5 points were preferred for 'clinical certainty' of change. However, more recently, in the Bradford trial of day hospital versus home physiotherapy after stroke (Young and Forster 1992), a statistically significant median difference between the two groups of 2 points was proposed as a clinically meaningful change, likely to be relevant to the patient and carer in limiting handicap after stroke. Arguably, even a 1 point increase could mean a major change (such as acquiring the ability to bathe independently after previously needing help), although it could just as easily represent a comparatively insignificant change (such as moving from needing major to minor help in transferring). The attachment of clinical significance to a quantitative change in a summed index made up of qualitatively different items is, therefore, problematic.

It would therefore seem expedient to, firstly, analyse whether there is any overall change in total Barthel score over time and then, secondly, to attempt to analyse what the change might mean. An analysis of individual items of the scale may help to either explain any observed differences in the total score or uncover fluctuations within items that may be hidden by an overall unchanged total (Wade *et al.* 1985). For example, Young and Forster (1992) found, in their trial of rehabilitation after stroke, that the home physiotherapy group had a significantly greater improvement than the day hospital group only on the stairs item. Young and Forster

(1992) also used a further approach to analysing Barthel scores. The range of total scores was collapsed into three bandings of 0-14, 15-19 and 20. Although no explanation of the rationale behind the bandings was given, earlier proposals by Wade and Langton Hewer (1987) would suggest the bandings could be defined as follows: *0-14, severe to moderate disability; 15-19, mild disability; 20, independent*. An analysis of the proportions of patients in each banding allowed changes in group status over time to be detected; indicating that score banding may also be a useful method of analysis. The extent to which a statistically significant change may, or may not, reflect clinically significance change should, however, be considered at all times. In this chapter, the analysis of Barthel Index scores will be presented as follows:

- *Graphical presentation of experimental and control group summed scores at baseline, 3 months and 12 months.*
- *Analysis of change in summed scores at 3 months and 12 months.*
- *Analysis of proportions in the 0-14, 15-19 and 20 score bandings at baseline, 3 months and 12 months.*
- *Analysis of individual item scores at baseline, 3 months and 12 months.*

2.2 METHOD OF ANALYSIS OF NOTTINGHAM HEALTH PROFILE RESULTS

Part one of the Nottingham Health Profile (NHP) was used to measure health status in the six areas of energy, pain, emotional reactions, sleep, social isolation and physical mobility.

As previously discussed in Chapter Two, the NHP is a standardised, self administered questionnaire, in which respondents answer yes or no to a collection of 38 statements, each relating to one of the six areas. Energy has three, sleep and social isolation five, pain and physical mobility eight and emotional reactions nine statements. The NHP questionnaire was independently completed by clients during the interviews conducted by research fieldworkers, at baseline, 3 months and 12 months.

A score was computed for each area of the profile, taking into account recommended weightings for each of the statements (Hunt *et al.* 1989). The weightings were developed by McKenna *et al.* (1981), following a series of 1200 interviews in which people were asked to make judgements about the relative seriousness of the statements by comparing each one with every other one in the same area. The weighted score for each area can fall on a limited number of incremental points between 0 and 100, depending on how many statements relate to each area. For example, for energy, which has only 3 statements (*I'm tired all the time*, *Everything is an effort*, *I soon run out of energy*, with severity weightings of 39.2%, 36.8% and 24% respectively for yes answers), the total score can fall on one of only 8 values: 0, 24, 36.8, 39.2, 60.8, 63.2, 76, 100. However, in the area of emotional reactions, which has 9 statements, each with different weighting, a much greater range of total scores is possible. Since a higher weighted score indicates a more serious problem, a score of 0 indicates no distress and 100 maximum distress in each of the areas, as measured by the profile.

The authors of the NHP have published a user's manual (Hunt *et al.* 1989), which sets out age, sex and social class norms for scores and makes recommendations for the administration and analysis of the profile. Each of the six areas of the NHP was considered separately, with data treated as ordinal, and subjected to appropriate non-parametric statistical analysis. A reduction in score was interpreted as an improvement and an increase as deterioration. There are no published criteria on how many points increase or decrease might constitute a meaningful clinical change. In this chapter, the analysis of Nottingham Health Profile scores will be presented as follows:

- *Graphical presentation of experimental and control group scores at baseline, 3 months and 12 months for each of the areas of energy, pain, emotional reactions, sleep, social isolation and physical mobility.*
- *Analysis of change in scores at 3 months and 12 months for each of the areas of energy, pain, emotional reactions, sleep, social isolation and physical mobility.*

2.3 METHOD OF ANALYSIS OF USE OF OTHER SERVICES

At the first interview, experimental and control group clients were given diary sheets to use for recording their use of services other than the DPS. Clients were asked to record the date and length of time of each contact with any of the following health or social services: district nurses, auxiliary nurses, chiropodists, speech therapists, occupational therapists, social workers, consultant physicians/surgeons, physiotherapists (other than those from the DPS) and visits to day hospitals. They were also asked to enter the dates of admission and discharge to hospital or respite care. Specially designed cards were inserted into clients' GP held medical notes, on which referring GPs were asked to record all their domiciliary and surgery contacts, and any referrals made to other professionals, for each client. Regular personal and telephone contacts were undertaken, to encourage good record keeping, but the motivation and cooperation of clients and GPs were probably the major factors determining the accuracy of the data.

Fieldworkers visited clients to collect completed diary sheets and, in the cases where there were no entries, they asked clients to verify that no contacts had been received. When GP record cards were collected from surgeries, the fieldworkers checked them against the GP held patient records, to make sure that every contact between the client and GP was recorded. In this chapter the analysis of clients' use of other services will be presented as follows:

- *Length of available follow-up time for collection of data.*
- *Spread and distribution of data.*
- *Analysis of differences between the experimental and control groups on*
 - contacts with single health and social services.*
 - total contacts with all health and social services.*
 - number of GP referrals.*
 - episodes of respite care.*
 - total length of stay in respite care.*
 - hospital admissions.*
 - total length of stay in hospital.*

3. SAMPLE ATTRITION

Sample attrition has implications that need to be considered when interpreting the results presented in this chapter. As previously discussed in the previous chapter (Chapter Three), there was sample attrition in both groups. With respect to the Barthel Index, experimental group data were collected at the first baseline interview from 93% of those referred (n=114), at 3 months from 84% (n=103) and at 12 months from 71% (n=87). In the control group, at the first interview, Barthel data were collected from 89% of those referred (n=108), at 3 months from 75% (n=92) and at 12 months from 62% (n=75). For the Nottingham Health Profile, sample sizes were slightly lower, as fieldworkers felt that some clients found some statements (e.g. emotional reactions statement *I feel that life is not worth living*, social isolation statement *I feel I am a burden to others*) particularly difficult or distressing to answer. In the experimental group, the NHP was completed at the first interview by 86% of those referred (n=106), at 3 months by 79% (n=97) and at 12 months by 61% (n=75). In the control group, at the first interview, the NHP was completed by 77% of those referred (n=94), at 3 months by 63% (n=77) and at 12 months by 52% (n=63). It should be noted that the number of cases for which NHP scores are presented varies slightly between the different areas of the NHP at each stage, as not all clients answered every statement related to each area.

With respect to data on use of services, client-held diary sheets were returned from all 222 subjects who were interviewed at the first stage (114 experimental and 108 control) and GP held record cards were obtained for 220 subjects (114 experimental and 106 control). Not all had been completed for the intended 18 months. Some clients who refused to be interviewed at various stages submitted diary sheets up to the time of withdrawal from the trial. Others who were referred towards the end of the recruitment phase had a reduced period of between 12 and 18 months for data collection. A total of 102 clients (46%) had the full 18 months, 66 (30%) had between 12 and 17 months and 54 (24%) had less than 12 months follow-up. There was no

difference between the experimental and control groups on the mean length of follow-up time (see Table 2, Chapter Two).

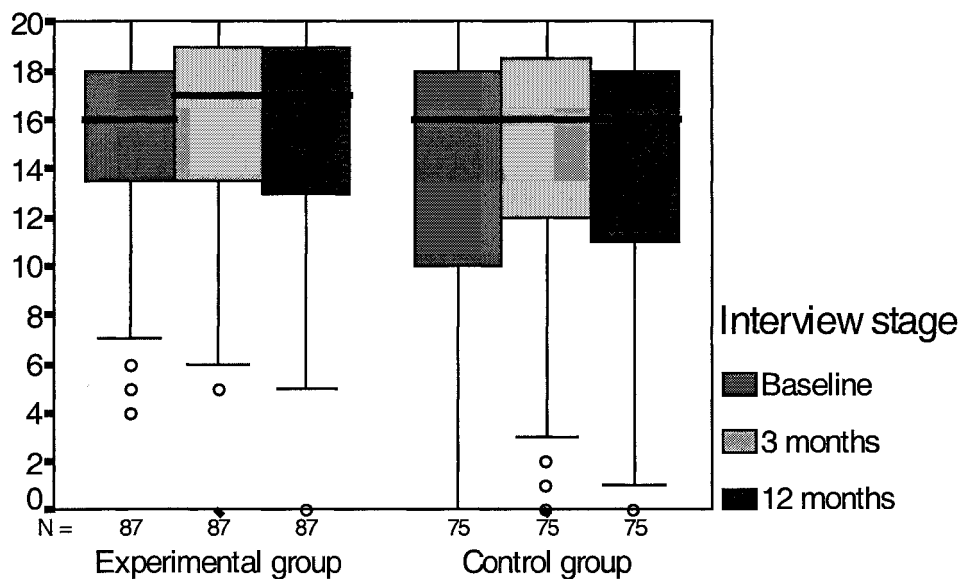
A full analysis of the characteristics of clients lost from the trial has already been presented (Chapter Three). In summary, clients (experimental and control) who dropped out of the trial, for any reason, were significantly worse on their initial Barthel Index score than clients remaining in the trial, at both the 3 and 12 month stages (Mann-Whitney U test, 3 month $p=0.004$, 12 month $p=0.02$). Dropouts were also significantly worse, at 3 months, on the baseline social isolation item of the NHP (Mann-Whitney U test, $p=0.001$) and, at 12 months, on the baseline social isolation and physical mobility items (social isolation $p=0.003$, physical mobility $p=0.005$). The trend for drop outs to be worse on both the baseline Barthel Index and some of the baseline NHP items was similar in separate experimental and control group comparisons (see Appendix 8, Tables 8.4 - 8.9). The loss of clients with lower initial Barthel scores and higher initial NHP scores (i.e. those less independent in activities of daily living and worse off in terms of health status) will inevitably have biased the sample and influenced the interpretation of Barthel and NHP results. To help minimise the bias caused by sample attrition, Barthel and NHP results will be presented only for clients who were interviewed at both the 3 and 12 month stages. Including subsequent dropouts in the 3 month analysis did not affect the results. However, some clients who refused to be interviewed agreed to carry on collecting diary data on their use of services. Analyses on use of services data will, firstly, be presented for the same cases as Barthel Index data and then, where appropriate, for all available cases with completed diary sheets.

4. BARTHEL INDEX RESULTS

4.1 GRAPHICAL PRESENTATION OF TOTAL BARTHEL INDEX SCORES AT BASELINE, 3 MONTHS AND 12 MONTHS

Figure 6 shows box plots of total Barthel Index scores for experimental and control groups at baseline, 3 months and 12 months. The upper and lower edges of the box correspond to the 75th and 25th percentiles and the median value is marked by a horizontal line inside the box. The vertical lines (known as whiskers) radiating from the box extend to the largest and smallest values, excluding outliers and extreme values. Outliers are values between 1.5 and 3 box-lengths from the upper or lower edges of the box and are represented by a circle. Extreme values are more than 3 box-lengths from the box and are represented by an asterisk.

Figure 6 Box plot of Barthel Index scores at baseline, 3 months and 12 months, for experimental group (n=87) and control group (n=75)



0 = poor ADL ability, 20 = good ADL ability

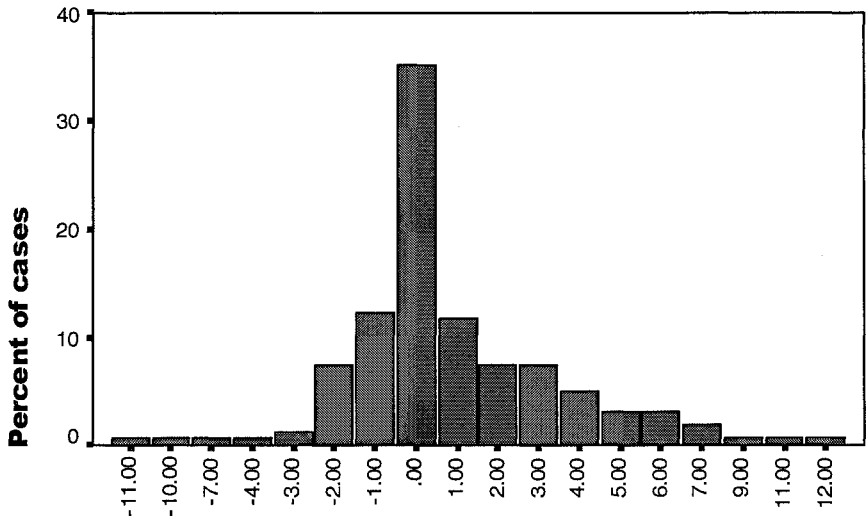
It can be seen from Figure 6 that the baseline median Barthel score was 16 for both the experimental and control groups. The experimental group median increased to 17 at 3 months and the one point improvement was maintained at 12 months. In the control group the initial median score remained unchanged throughout both the 3 and 12 month stages.

4.2 ANALYSIS OF CHANGE IN TOTAL BARTHEL INDEX SCORES AT 3 AND 12 MONTHS

Although the experimental and control groups were comparable on their Barthel scores at the baseline measure, comparability on unknown variables can never be assumed. Because of the problems of differential sample attrition highlighted in the previous section, change scores (rather than subjects' score at a defined point) were used to test whether or not Domiciliary Physiotherapy improved clients' level of independence in activities of daily living. Although it is common practice to use subjects' status at a defined point in the study, it is better to use change from the baseline as an outcome measure (Altman 1991) in order to reduce the effect of any unknown differences between the two groups. Change scores were calculated by subtracting the initial score from the 3 month and 12 month scores. A positive change indicates

improvement. Figures 7 and 8 below show bar charts of change scores at 3 months and 12 months for the experimental and control groups combined.

Figure 7 Bar chart to show change in Barthel Index score at 3 months (experimental and control groups combined, n = 162)

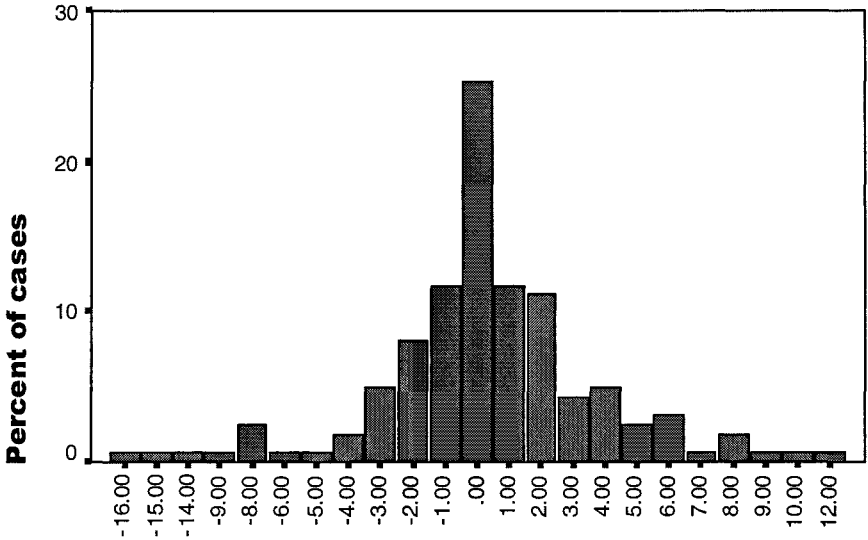


Change in Barthel Index score at 3 months

N = 162

median = 0

Figure 8 Bar chart to show change in Barthel Index score at 12 months (experimental and control groups combined, n = 162)



Change in Barthel Index score at 12 months

N = 162

Median = 0

It can be seen from Figures 7 and 8 that most clients either stayed the same or improved/deteriorated to a small degree. The median change scores were 0, at 3 and 12 months in both the experimental and control groups, indicating that the null hypothesis can not be rejected. There was no evidence that domiciliary physiotherapy made any difference to clients' level of functional ability, as measured by the Barthel Index. There was, however, a wide range of change scores, with extreme outliers in both the experimental and control groups. Scores ranged from -11 to +12 at 3 months and from -16 to +12 at 12 months. The proportion of clients who improved will now be compared with the proportions who did not change and who deteriorated. Clients who improved will then be compared, on their baseline Barthel score, with those who did not change/deteriorated. The following simple definitions of change in score were applied: *negative change score = deterioration, change score of 0 = no change, and positive change score = improvement*. Tables 9 and 10 overleaf show the proportions in each group who had deteriorated, stayed the same or improved at 3 and 12 months.

Table 9 Proportions who deteriorated, stayed the same and improved on the Barthel Index score at 3 months in the experimental group (n=87) and the control group (n=75)

Change score	Experimental group	Control group
<0 (deteriorated)	24 (28%)	14 (19%)
0 (no change)	26 (30%)	31 (41%)
>0 (improved)	37 (42%)	30 (40%)
Total	87 (100%)	75 (100%)

Chi-square=2.93, 2 tailed p=0.23

Table 10 Proportions who deteriorated, stayed the same and improved on the Barthel Index score at 12 months in the experimental group (n=87) and the control group (n=75)

Change score	Experimental group	Control group
<0 (deteriorated)	31 (36%)	22 (29%)
0 (no change)	20 (23%)	21 (28%)
>0 (improved)	36 (41%)	32 (43%)
Total	87 (100%)	75 (100%)

Chi-square=0.90, 2 tailed p=0.64

It can be seen from the above tables that there were no significant differences between the two groups, at either stage, on the proportions of clients who had improved, deteriorated or stayed the same. However, further analysis revealed some important differences between those who improved and those that did not change or deteriorated. Tables 11 and 12 show the baseline Barthel scores for clients in the three categories.

Table 11 Baseline median Barthel Index scores of clients who improved, deteriorated or did not change at 3 months for experimental group (n=87) and control group (n=75)

EXPERIMENTAL GROUP (N=87)		
deteriorated (n=24)	no change (n=26)	improved (n=37)
median Barthel = 17 25 th -75 th percentiles (14-18)	median Barthel = 18 25 th -75 th percentiles (13.5-20)	median Barthel = 14 25 th -75 th percentiles (9.5-16)
CONTROL GROUP (N=75)		
deteriorated (n=14)	no change (n=31)	improved (n=30)
median Barthel = 17 25 th -75 th percentiles (10.5-18.25)	median Barthel = 17 25 th -75 th percentiles (12-19)	median Barthel = 12 25 th -75 th percentiles (8-16)

Table 12 Baseline median Barthel Index scores of clients who improved, deteriorated or did not change at 12 months for experimental group (n=87) and control group (n=75)

EXPERIMENTAL GROUP (N=87)		
deteriorated (n=31)	no change (n=20)	improved (n=36)
median Barthel = 17 25 th -75 th percentiles (14-18)	median Barthel = 18.5 25 th -75 th percentiles (15.5-20)	median Barthel = 14 25 th -75 th percentiles (10.25-16)
CONTROL GROUP (N=75)		
deteriorated (n=22)	no change (n=21)	improved (n=32)
median Barthel = 16.5 25 th -75 th percentiles (12.75-18)	median Barthel = 18 25 th -75 th percentiles (15.5-20)	median Barthel = 11 25 th -75 th percentiles (9-16)

Tables 11 and 12 show that the median baseline Barthel scores for clients who improved were lower (i.e. worse), and those of clients who deteriorated/did not change were higher, than the overall sample median of 16. Using the Mann-Whitney U test, to compare the median scores of those who improved with the combined group of those who deteriorated/did not change, demonstrates that those who improved, at both 3 and 12 months, scored significantly less on the

initial Barthel Index measure than those who deteriorated/stayed the same (3 month $U=2790$, $p=0.00$; 12 month $U=1812$, $p=0.00$). Therefore, if 'improvers' were those who were significantly worse to start with and, as previously discussed, drop outs were those who scored significantly less on their baseline Barthel score than those who stayed in the trial, then it appears that the trial lost those clients most likely to show measurable improvement, thereby possibly obscuring a significant difference. A possible reason why some of the 'better' cases, i.e. those with a higher baseline Barthel score, did not show any measurable improvement could be the ceiling effect of the Barthel scale. The highest possible score is 20 and the median baseline score of the 'no change' group was 18, leaving little room on the scale for improvement.

Loss of the worst cases is, therefore, one possible explanation for the failure to reject the null hypothesis that domiciliary physiotherapy made no difference to clients' level of functional ability as measured by the Barthel Index. Other possible reasons for failing to reject the null hypothesis are considered at the end of this chapter. In order to further explore the data for any hidden trends, the score-banding approach mentioned earlier in this chapter is presented in the next section.

4.3 ANALYSIS OF BARTHEL INDEX SCORE BANDINGS OF ATTAINMENT

In keeping with the method of analysis by Young and Forster (1992) in their trial of stroke rehabilitation, Tables 13,14 and 15 show results using the following bandings of attainment: *0-14, severe to moderate disability; 15-19, mild disability and 20 independent*. These analyses represent snapshots at 3 points in time, baseline, 3 and 12 months.

Table 13 Barthel Index score bandings at baseline in the experimental group (n=87) and the control group (n=75)

Barthel score	Experimental group	Control group
0-14 (severe/moderate disability)	32(37%)	31(41%)
15-19 (mild disability)	42(48%)	35(47%)
20 (independent)	13(15%)	9(12%)
Total	87(100%)	75(100%)

Chi-square=0.50, 2 tailed p=0.78

Table 14 Barthel Index score bandings at 3 months in the experimental group (n=87) and the control group (n=75)

Barthel score	Experimental group	Control group
0-14 (severe/moderate disability)	25(29%)	26(35%)
15-19 (mild disability)	43(49%)	37(49%)
20 (independent)	19(22%)	12(16%)
total	87(100%)	75(100%)

Chi-square=1.12, 2 tailed p=0.56

Table 15 Barthel Index score bandings at 12 months in the experimental group (n=87) and the control group (n=75)

Barthel score	Experimental group	Control group
0-14 (severe/moderate disability)	32(37%)	27(36%)
15-19 (mild disability)	38(44%)	37(49%)
20 (independent)	17(19%)	11(15%)
total	87(100%)	75(100%)

Chi-square=0.84, 2 tailed p=0.66

It can be seen from tables 13,14 and 15 that the two groups were initially comparable on the proportions in each of the 3 bands (chi-square p=0.78). At 3 months there was a similar increase, in both groups, in the proportions who were mildly disabled or fully independent.

There was then little change at 12 months, from the 3 month stage. The final method of exploratory analysis involved looking at all individual items of the Barthel Index and is discussed in the next section.

4.4 ANALYSIS OF INDIVIDUAL ITEMS OF THE BARTHEL INDEX

Appendix 9 contains cross tabulations, by experimental and control group, of scores for all the individual items of the Barthel Index, at initial referral, 3 months and 12 months. These tables are included mainly for descriptive purposes, although the chi-square statistic and p values are shown. No statistically significant differences, where there were not more than 20% of cells in the contingency table with expected frequencies of less than 5, were found for any item.

However, the stairs item warrants further consideration. The crosstabulation at 3 months shows that there were significantly more clients in the experimental group who were independent on stairs ($p=0.05$), although there were 33% of cells with expected frequencies of less than 5. To eliminate the problem of too many cells with low expected frequencies, the three scoring categories within the stairs item were collapsed into two (independent on stairs against needing help or unable to climb stairs), which resulted in a borderline significant 3 month p value of 0.056 (see Appendix 9). This finding is worthy of mention, as the Bradford Stroke Trial (Young and Forster 1992) found that the home treatment group were better than the Day Hospital group on the stairs item of the Barthel Index.

5. NOTTINGHAM HEALTH PROFILE RESULTS

5.1 GRAPHICAL PRESENTATION OF NHP SCORES AT BASELINE, 3 MONTHS AND 12 MONTHS

Figures 9 to 14 show box plots of scores in the areas of energy, pain, emotional reactions, sleep, social isolation and physical mobility for experimental and control groups at baseline, 3 months and 12 months. As for the Barthel Index results, only those who were interviewed at all 3 stages

are shown. The number of cases for which complete scores were obtained varies for each area of the profile.

Figure 9 Box plot of Nottingham Health Profile energy scores at baseline, 3 months and 12 months for experimental group (n=73) and control group (n=61)

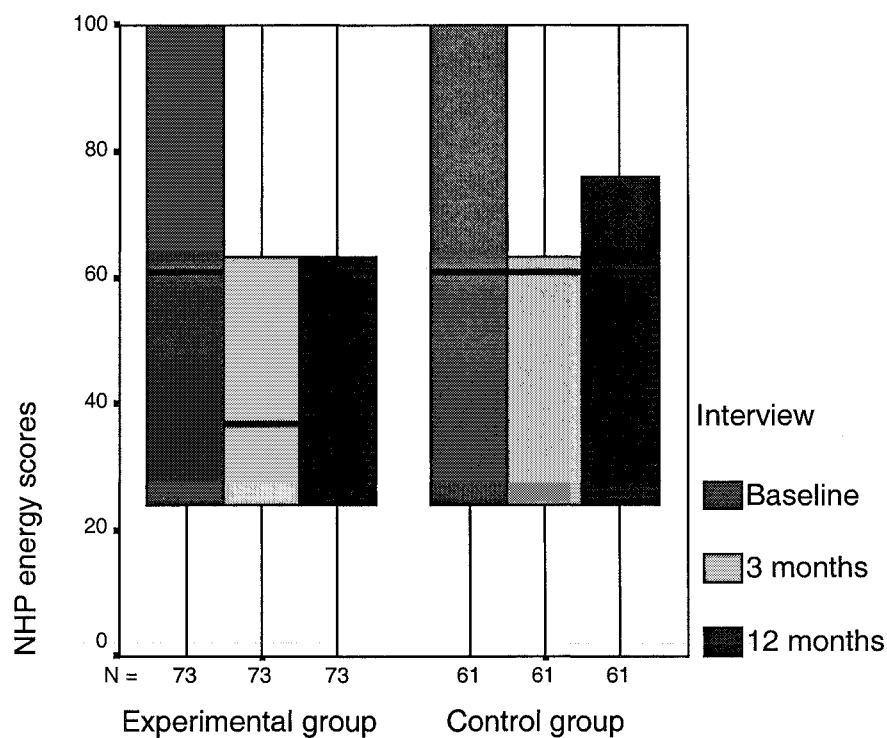


Figure 10 Box plot of Nottingham Health Profile pain scores at baseline, 3 months and 12 months for experimental group (n=70) and control group (n=60)

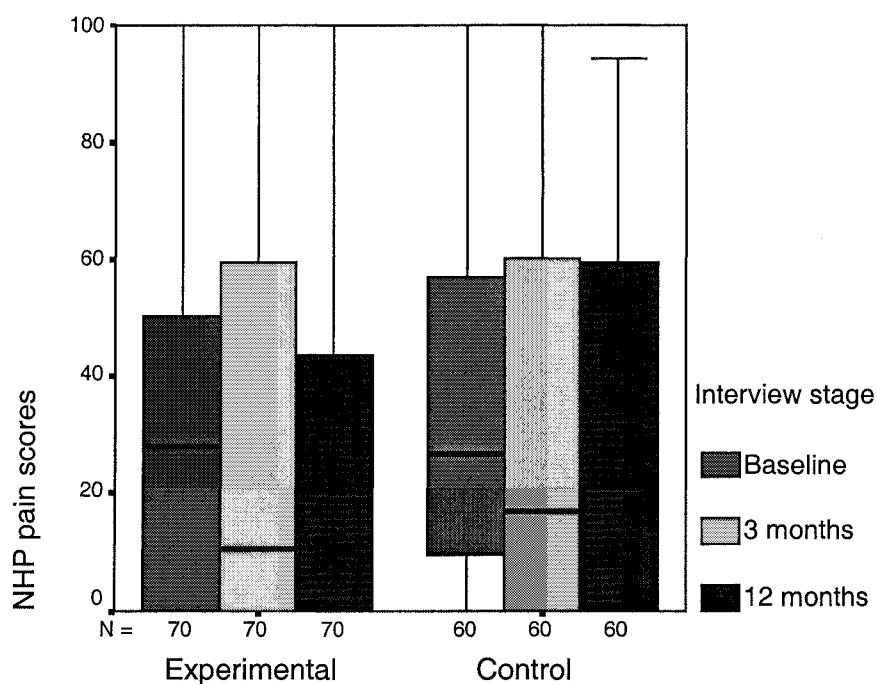


Figure 11 Box plot of Nottingham Health Profile emotions scores at baseline, 3 months and 12 months for experimental group (n=71) and control group (n=60)

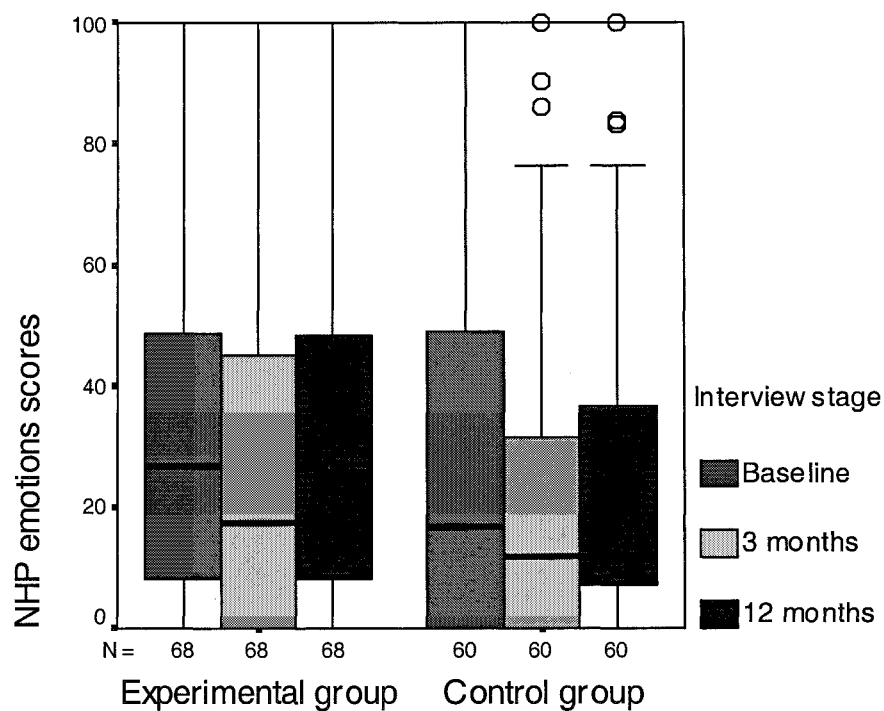


Figure 12 Box plot of Nottingham Health Profile sleep scores at baseline, 3 months and 12 months for experimental group (n=71) and control group (n=59)

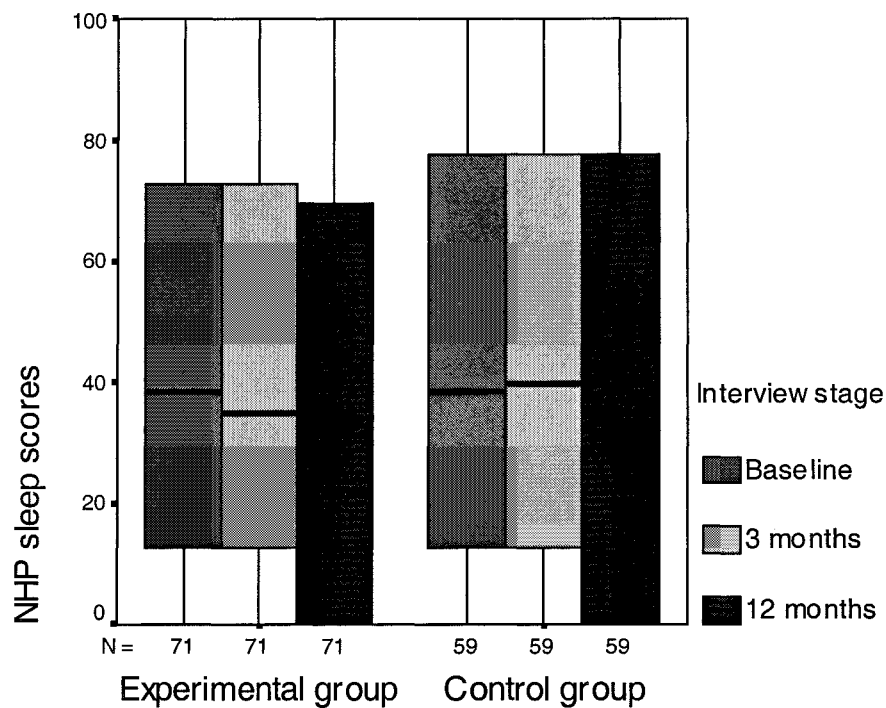


Figure 13 Box plot of Nottingham Health Profile social scores at baseline, 3 months and 12 months for experimental group (n=69) and control group (n=59)

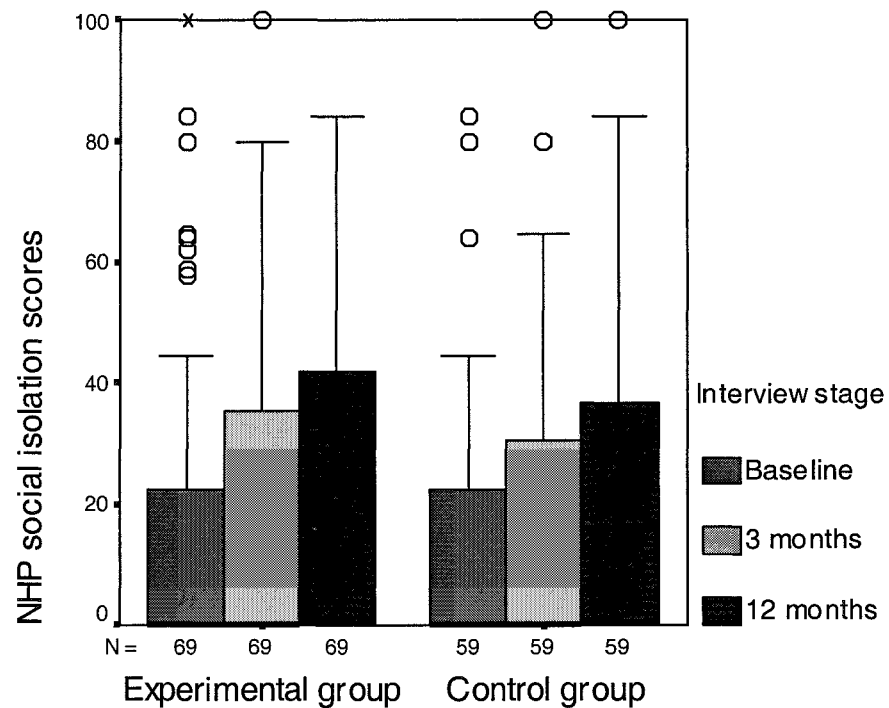
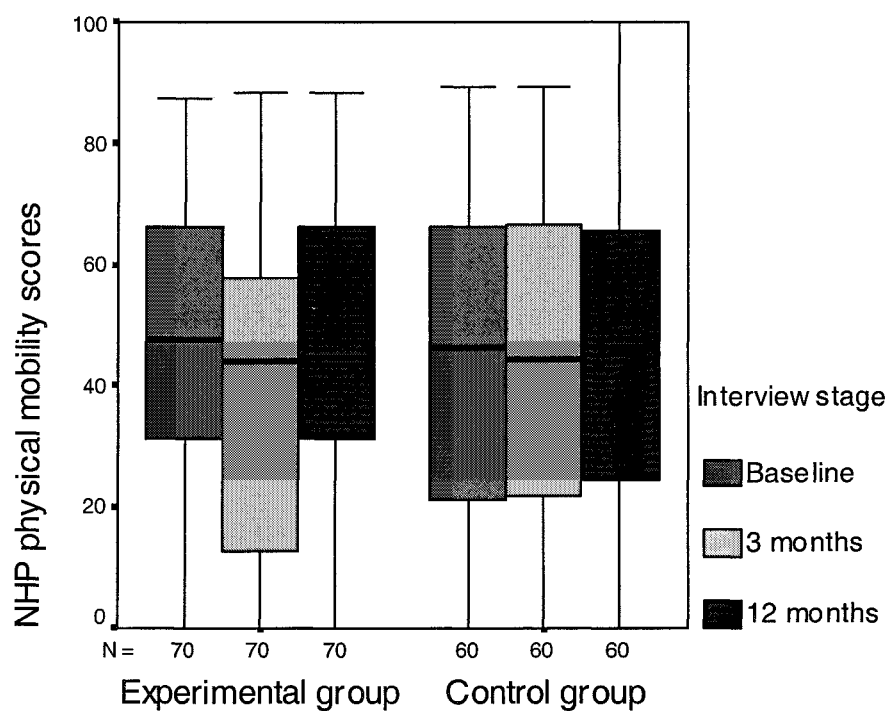


Figure 14 Box plot of Nottingham Health Profile physical mobility scores at baseline, 3 months and 12 months for experimental group (n=70) and control group (n=60)



In all six areas the plots show similar pictures for the experimental and control groups. There is little notable change over time, with equivalent experimental and control group median values staying relatively constant. The analysis of change in scores, presented in the following sections, examines the data more closely.

5.2 ANALYSIS OF CHANGE IN NOTTINGHAM HEALTH PROFILE SCORES AT 3 AND 12 MONTHS

As discussed in the previous chapter, there were no significant differences between the two groups in baseline scores in any of the six areas, demonstrating that the experimental and control groups were comparable at the baseline measure. However, as stated in the previous section on the Barthel Index results, comparability on unknown variables can never be assumed and there was a problem of differential sample attrition in this study. Therefore, change scores (rather than subjects' score at a defined point) were again used to test whether or not Domiciliary Physiotherapy improved clients' health status. As for the Barthel Index, change scores were calculated (only for subjects present at all stages) by subtracting the initial score from the 3 month and 12 month scores. It should be noted that in the Nottingham Health Profile (unlike the Barthel Index) a positive change indicates deterioration.

As already explained, each area has a different number of statements from which the total score is calculated, so that in areas with several statements, there were many possible total scores and an even greater number of possible change scores. For example in the area of emotional reactions there were 77 different change scores at 3 months, ranging from -84 to 64. Graphical presentation of change scores is not shown, as bar charts for such widely distributed data would consist, by necessity, of very many narrow bars. Instead, summary statistics for change scores are shown in Table 16. In order to test whether there were any statistically significant differences between the experimental and control groups in the magnitude and direction of change scores, the Mann-Whitney U test was used as the most appropriate non-parametric test

for detecting differences between two independent samples. The test ranks the data from both samples and compares the difference between the mean ranks for each group. The results of the Mann-Whitney U tests for differences in the magnitude of change scores are also shown in Table 16.

Table 16 Differences between experimental and control groups on magnitude of change in NHP score at 3 and 12 months

Area of NHP	Median (25th-75th percentile) change score at 3 months		Mann-Whitney U statistic & 2-tailed p corrected for ties	Median (25th-75th percentile) change score at 12 months		Mann-Whitney U statistic & 2-tailed p corrected for ties
	Experimental group	Control group		Experimental group	Control group	
Energy	0 (-37 - 0) [n=73]	0 (-37 - 0) [n=61]	U=2226.0 p=0.10	0 (-37 - 24) [n=73]	0 (-37 - 0) [n=61]	U=2206.5 p=0.67
Pain	0 (-20 - 4) [n=70]	-2 (-16 - 10) [n=60]	U=2077.0 p=0.91	-5 (-20 - 2) [n=70]	-6 (-20 - 0) [n=60]	U=2196.5 p=0.86
Emotions	-5 (-17 - 4) [n=68]	0 (-16 - 5) [n=60]	U=1990.5 p=0.81	0 (-15 - 11) [n=68]	0 (-10 - 7) [n=60]	U=2098.0 p=0.63
Sleep	0 (-13 - 0) [n=71]	0 (-13 - 13) [n=59]	U=1947.5 p=0.49	0 (-21 - 4) [n=71]	0 (-21 - 0) [n=59]	U=2225.0 p=0.98
Social	0 (0 - 16) [n=69]	0 (0 - 16) [n=59]	U=2017.0 p=0.92	0 (-3 - 19) [n=69]	0 (0 - 21) [n=59]	U=2158.0 p=0.84
Physical mobility	-3 (-12 - 0) [n=70]	0 (-11 - 11) [n=60]	U=1706.0 p=0.07	0 (-14 - 10) [n=70]	0 (-11 - 11) [n=60]	U=2037.5 p=0.37

The median change scores all indicated either slight improvement (negative change score) or no change (zero change score). There were no statistically significant differences between the experimental and control groups, in any area of the NHP, at either the 3 or 12 month stages. However, it should be noted that the 3 month change in physical mobility approached significance ($p=0.07$), with the experimental group showing a 3 point improvement against a zero improvement in the control group. Because of its focus on physical performance, physiotherapy may be more likely to affect physical mobility than the other areas of the NHP. This finding may be relevant to the effectiveness of the intervention.

If the NHP data were to be analysed in the same way as the Barthel, the proportion of clients who improved could now be compared with the proportions who did not change and who deteriorated. However, because of the nature of weighted scores in the NHP (discussed earlier in this chapter) it proved difficult to reliably classify clients into those who deteriorated/stayed the same/improved. In some areas, change scores clustered around zero, with several scores between 0 and -1 and between 0 and +1, making a distinctive no change score difficult to define. In order to further explore the data and uncover possible reasons for the failure to reject the null hypothesis, a simple definition of *negative change score = improvement* was used to separate those who improved from those who did not change/deteriorated. In keeping with the method of analysis of the Barthel Index, those who improved were compared, on their baseline median NHP scores, with those who deteriorated/did not change. Table 17 shows the results of the comparisons.

Table 17 Comparisons of baseline median NHP scores for clients who improved against those who deteriorated/did not change, at 3 months and 12 months, for experimental group and control group

	Median (25th-75th percentiles) at 3 months			Median (25th-75th percentiles) at 12 months		
Baseline NHP scores	Deteriorated /no change	Improved	Mann- Whitney U statistic & 2- tailed p corrected for ties	Deteriorated/ no change	Improved	Mann- Whitney U statistic & 2- tailed p corrected for ties
Energy	60.8 (24-100) n=84	69.6 (60.8-100) n=50	U=1938 p=0.000	36.8 (0-100) n=103	63.2 (60.8-100) n=31	U=1256 p=0.000
Pain	11.2 (0-44.4) n=89	37.9 (19.4-80.3) n=41	U=1777.5 p=0.000	0 (0-34.5) n=97	36.8 (20.7-79.9) n=33	U=863.5 p=0.000
Emotions	7.1 (0-24.7) n=85	46 (23.9-76.3) n=46	U=1004.5 p=0.000	10.5 (0-38.8) n=81	38.16 (16.8-66.9) n=50	U=1051 p=0.000
Sleep	34.9 (0-77.6) n=84	56.6 (34.9-77.6) n=46	U=2118.5 p=0.0035	31.5 (0-77.6) n=98	53.5 (34.9-77.6) n=32	U=1393 p=0.0051
Social	0 (0-22.5) n=82	42.2 (22.5-63.9) n=46	U=1244.5 p=0.000	0 (0-22.5) n=84	41.9 (22.5-57.9) n=44	U=1249 p=0.000
Physical mobility	50.3 (23-67.2) n=81	55.5 (42.9-69.4) n=49	U=2145 p=0.0015	43.9 (18.2-57.7) n=79	56.69 (37-69.4) n=51	U=1327 p=0.0003

Table 17 shows that ‘improvers’ were significantly worse on all baseline NHP scores than those who deteriorated/did not change. As drop-outs from the trial were found to be significantly worse at 3 and 12 months on the initial social isolation score and at 12 months on the initial physical mobility score, the loss of the more socially isolated and less mobile cases may well have removed from the trial cases who were most likely to improve. Once again, the loss of worst cases may have reduced the extent to which measurable effects of the DPS could be demonstrated.

6. CLIENTS' USE OF OTHER SERVICES

The following sections will present data on clients' use of other services. As mentioned earlier in this chapter, data on clients' use of other services were collected from clients and GPs.

Client-held diaries were returned from 222 clients (114 experimental and 108 control) and GP record cards were obtained for 220 clients (114 experimental and 106 control). In previous sections of this chapter, data were presented only from clients who were interviewed at all 3 stages, which served to reduce the sample size to 162 (87 experimental and 75 control) for Barthel results and to as low as 128 (68 experimental and 60 control) for NHP results. In order to be consistent, the use of services results will be presented for the same sample as Barthel results (to be referred to as 'sample 1'). However, data will also be presented using all available diary and record card data (to be referred to as 'sample 2') where the inclusion of the extra cases yielded different results.

6.1 LENGTH OF FOLLOW-UP TIME FOR USE OF SERVICES DATA

The available length of follow up time for collection of data on clients' contacts with other health and social services was discussed earlier in Chapter Two (Methods). The mean length of follow-up time for sample 1 and sample 2 is shown in Table 18.

Table 18 Follow-up time (months) for sample 1 and sample 2, by experimental and control groups

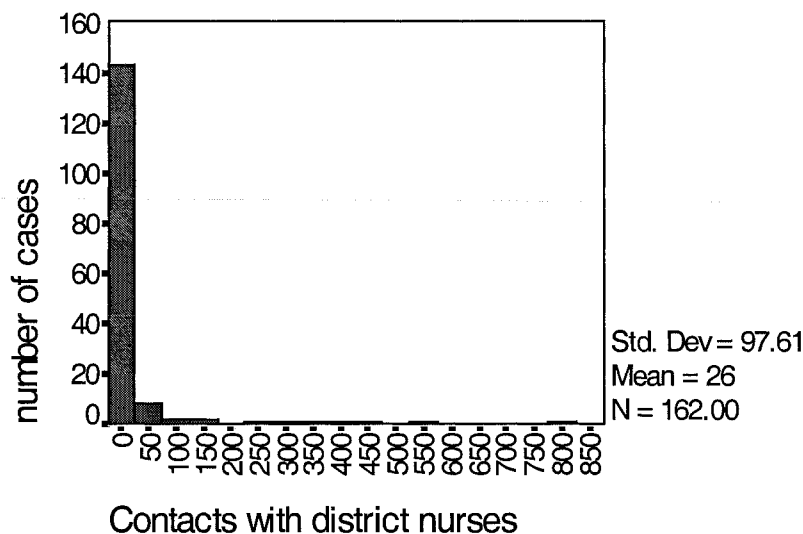
Sample 1	Follow-up time (months) mean (SD)
Experimental group n=87	16.92 (1.93)
Control group n=75	16.51 (3.11)
t=1.02, p=0.31	
Sample 2	Follow-up time (months) mean (SD)
Experimental group n=114	14.11 (5.80)
Control group n=108	13.35 (6.05)
t=0.95, p=0.35	

It can be seen from the Table 18 that there was no statistically significant difference between the two groups, in follow-up time, for either sample 1 or sample 2. Follow-up time in sample 1 is less widely distributed than in sample 2.

6.2 CLIENTS' CONTACTS WITH OTHER SERVICES

Clients had contacts with the following services: district nurses, auxiliary nurses, out-patient physiotherapists, hospital consultants, occupational therapists, social workers, chiropodists, speech therapists, GPs and day hospitals. It was found that, for most health and social services, number of client contacts was not normally distributed. As an illustration, Figure 15 shows a histogram of the number of contacts with district nurses for sample 1.

Figure 15 Histogram of clients' contacts with District Nurses (Sample 1, n=162)



It can be seen from Figure 15 that the majority of clients received either no contacts or a relatively small number of contacts with District Nurses and a few outlying cases received large numbers of contacts. The skewed distribution shown is very similar for sample 2 and is highly typical of the distribution of data on contacts with other individual services. Appendix 10 contains histograms, for sample 1, of contacts with auxiliary nurses, out-patient physiotherapists, consultants, occupational therapists, social workers, chiropodists, speech therapists, GPs, cumulated health contacts, cumulated social services contacts and total (health

and social services) contacts. The distribution of contacts data shows that a few individuals used large amounts of health and social services. Logistic regression was carried out to see if any known variables could predict use of services. Neither age, gender, housing, living alone, having a carer, Barthel score, or NHP score were significant covariates, at the 0.05 level, in the prediction of none versus some contacts with health/social services. Arber and Ginn (1990), in their analysis of care for lone older people, based on the 1985 General Household Survey, suggested that elderly people living alone were quite well targeted by services, and that carers often alerted service providers to their needs. Therefore, living alone and/or having a carer could be predictors of the likelihood of service use, although this was not detected by the logistic regression model. Arber and Ginn (1990) did not find any association between housing tenure, gender, marital status or income and use of services.

6.3 ANALYSIS OF DIFFERENCES BETWEEN THE EXPERIMENTAL AND CONTROL GROUPS ON CONTACTS WITH OTHER SERVICES

Although number of contacts constitutes ratio-level data, the skewed distribution did not permit the routine use of a parametric statistic, such as the t-test, to test the differences between group means. Even a non-parametric equivalent, such as the Mann-Whitney U test, was often inappropriate as the large number of cases with no contacts created many tied ranks, making the test insensitive. To overcome these problems, contacts with individual services were collapsed to a simple categorical level. Data were analysed according to whether clients received *none* or *one or more* contacts with each service. Following the categorical analysis, the sub-groups of clients who received at least one contact were analysed separately. Mann-Whitney U Tests were used to test the sub-groups for any differences between experimental and control clients in the number of contacts. Contacts with individual services were analysed first, followed by cumulated contacts with health and social services and then total contacts (health and social services).

6.3.1 *Contacts with individual services*

Appendix 11 contains cross-tabulations, for each individual service, of *none* versus *one or more* contacts, by experimental and control groups. The data from sample 1 (i.e. only those clients who were interviewed at all three stages, n=162) has been used for these cross-tabulations. The services clients were most likely to be in contact with were the District Nursing Service (i.e. District Nurses and Auxiliary Nurses), Hospital Consultants and GPs. District nursing services have been shown to be major players in support and care for the elderly and their carers (Caldock 1990). Chi-square tests showed no significant differences between the experimental and control groups, in the proportions of clients having none or one or more contacts with any individual service. Re-analysis using sample 2 (i.e. all available data, regardless of whether clients dropped out of the interview schedule) did not change the significance of the results. The analysis of sub-groups of clients who received at least one contact is presented in Table 19.

Table 19 Descriptive statistics of contacts with individual services and Mann-Whitney U-tests to compare experimental and control groups who had more than one contact.

Services	Min	Max	Mean (SD)	Median (IQR)	Sub-sample with at least one contact: Experimental (Exp) n Control (Con) n Mann-Whitney 2-tailed p corrected for ties
District Nurses					
Experimental group n=87	0	806	23.4 (104.8)	0 (0-7)	Exp n=43, Con n=39
Control group n=75	0	468	30.1 (89.1)	1 (0-6)	p=0.84
Auxiliary Nurses					
Experimental group n=87	0	1488	48.9 (222.7)	0 (0-0)	Exp n=18, Con n=21
Control group n=75	0	468	17.1 (57.4)	0 (0-12)	p=0.91
Out Patient Physiotherapists					
Experimental group n=87	0	26	0.7 (3.3)	0 (0-0)	Exp n=7, Con n=11
Control group n=75	0	42	1.7 (7.1)	0 (0-0)	p=0.62
Hospital Consultants					
Experimental group n=87	0	30	2.5 (4.4)	1 (0-4)	Exp n=46, Con n=44
Control group n=75	0	16	2.6 (3.5)	1 (0-4)	p=0.97
Social Services Occupational Therapists					
Experimental group n=87	0	8	0.4 (1.3)	0 (0-0)	Exp n=8, Con n=7
Control group n=75	0	16	0.5 (2.2)	0 (0-0)	p=0.86
Social Workers					
Experimental group n=87	0	7	0.5 (1.3)	0 (0-0)	Exp n=19, Con n=15
Control group n=75	0	6	0.5 (1.3)	0 (0-0)	p=0.77
Domiciliary Chiropodists					
Experimental group n=87	0	15	0.6 (1.9)	0 (0-0)	Exp n=15, Con n=8
Control group n=75	0	9	0.3 (1.3)	0 (0-0)	p=0.90
Clinic Chiropodists					
Experimental group n=87	0	7	0.5 (1.4)	0 (0-0)	Exp n=12, Con n=13
Control group n=75	0	16	0.7 (2.4)	0 (0-0)	p=0.76
Domiciliary Speech Therapists					
Experimental group n=87	0	16	0.5 (2.3)	0 (0-0)	Exp n=6, Con n=3
Control group n=75	0	3	0.1 (0.5)	0 (0-0)	p=0.43
GPs in the surgery					
Experimental group n=87	0	22	2.8 (4.9)	0 (0-4)	Exp n=35, Con n=27
Control group n=74	0	21	2.2 (4.5)	0 (0-2)	p=0.34
GPs at home					
Experimental group n=87	0	62	8.6 (10.6)	5 (2-11)	Exp n=72, Con n=62
Control group n=74	0	37	8.3 (8.6)	5.5 (1-11)	p=0.95
Day Hospitals					
Experimental group n=87	0	22	0.4 (2.6)	0 (0-0)	Exp n=4, Con n=5
Control group n=75	0	142	0.4 (19.4)	0 (0-0)	Exact 2-tailed p=0.04

It can be seen from Table 19 that, with one exception, once contact with any service had been established there were no statistically significant differences between the two groups on the numbers of contacts. Visits to day hospitals was the exception. In the sub-sample of clients who visited day hospitals, the control group made significantly more visits than the experimental group (Exact 2-tailed $p=0.04$). Although there were only 9 cases in Sample 1 (4 experimental and 5 control), the difference is worthy of note. The null hypothesis that domiciliary physiotherapy made no difference to clients use of other services can not be rejected overall. However, there is evidence that domiciliary physiotherapy may have reduced client contacts with day hospitals. Young and Forster (1992) have previously studied the relationship between domiciliary physiotherapy intervention and use of day hospitals. They found that, for stroke patients, domiciliary physiotherapy was more effective than day hospital attendance, which adds weight to the finding in this study that domiciliary physiotherapy reduced clients' day hospital visits. It is worthy of note that contacts with out-patient physiotherapists were minimal and, as they were not greater in the control group, there is no evidence to suggest that outpatient physiotherapy was used as a substitute for domiciliary physiotherapy.

6.3.2 Cumulated contacts with health and social services

Appendix 12 contains cross-tabulations for cumulated health service contacts, cumulated social services contacts and total (health and social services) contacts, of *none* versus *one or more* contacts, by experimental and control groups. The data from sample 1 (i.e. only those clients who were interviewed at all three stages, $n=162$) has been used for these cross-tabulations. Only 46 clients (28%) had contacts with social services, compared with 159 clients (98%) who had contacts with health services. Therefore, in general, health services were more likely than social services to be in contact with clients. Once contacts with individual services were added together, the data were still positively skewed, but the number of clients with no contacts was reduced to only two. The very small number of clients with no total contacts would indicate that those who had no contacts with individual services were not all the same clients, i.e. that

there was not a 'core group' of clients who received no contacts with any service. For sample 1, there were no significant differences between the experimental and control groups in the proportions of clients having no contacts or one or more contacts with health and /or social services (see Appendix 12). However, for sample 2, the additional contacts data obtained from those who dropped out of the interview schedule altered the distribution of the data sets for cumulated health contacts, cumulated social services contacts and total (health and social services) contacts by increasing the number of clients with no contacts. Out of the additional 74 diaries/record cards returned from those who had dropped out of the interview schedule, 22 (30%) recorded no contacts with health services and 17 (77%) of these 22 were from control group clients. Fieldworkers asked clients to verify that diaries with no entries were a 'true' record of no contacts, rather than a failure to fill in the sheets, and they checked GP record cards against clients' medical records. Therefore, since control group dropouts often cited lack of contact with services as a reason for not wanting to cooperate with the interview schedule, it would seem valid to include their contacts data in the results. Tables 20, 21 and 22 overleaf show cross-tabulations, by experimental and control group, of *none* versus *one or more* cumulated contacts with health services, social services and total (health and social) services for sample 2.

Table 20 Cross-tabulation, by experimental and control group, of number of cumulated contacts (none versus one or more) with health services for sample 2 (n=235)

Contacts	Experimental group	Control group
None	6 (5%)	18 (16%)
One or more	114 (95%)	97 (84%)
Total	120 (100%)	115 (100%)

Chi-square=7.27 (1 DF) p=0.007

Table 21 Cross-tabulation, by experimental and control group, of number of cumulated contacts (none versus one or more) with social services for sample 2 (n=238)

Contacts	Experimental group	Control group
None	86 (72%)	97 (82%)
One or more	34 (28%)	21 (18%)
Total	120 (100%)	118 (100%)

Chi-square=3.72 (1 DF) p=0.05

Table 22 Cross-tabulation, by experimental and control group, of number of cumulated contacts (none versus one or more) with health and social services for sample 2 (n=235)

Contacts	Experimental group	Control group
None	6 (5%)	18 (16%)
One or more	114 (95%)	97 (84%)
Total	120 (100%)	115 (100%)

Chi-square=7.27 (1 DF) p=0.007

Tables 20, 21 and 22 show that in the experimental group there was a statistically significantly lower proportion of clients with no contacts with health services (p=0.007), social services (p=0.05) and health/social services combined (p=0.007). On the basis of Sample 2 data, domiciliary physiotherapy significantly increased (rather than decreased) the likelihood of

clients having one or more contacts with another service. The experimental hypothesis relating to use of services, i.e. that domiciliary physiotherapy will reduce use of other health and social services, has not been proved. The data from sample 2 seem to indicate that domiciliary physiotherapists acted as gatekeepers to health and social services. The gatekeeping role of domiciliary physiotherapists will be further discussed in the next chapter. However, it should be noted that among those who had gained access to services, there were no significant differences between the two groups on number of cumulated contacts (see Table 23).

Table 23 Descriptive statistics of cumulated contacts with health and social services and Mann-Whitney U- tests to compare experimental and control groups who had more than one contact.

Services	Min	Max	Mean (SD)	Median (IQR)	Sub sample with at least one contact Experimental (Exp) n Control (Con) n Mann-Whitney 2-tailed p corrected for ties
All Health Services					
Experimental group n=87	0	1643	89.8 (282.4)	20 (10-44)	Exp n=87, Con n=74 p=0.43
Control group n=74	0	944	68.9 (141.1)	25.5 (8.5-60)	
All Social Services					
Experimental group n=87	0	17	1.3 (3.1)	0 (0-1)	Exp n=26, Con n=20 p=0.76
Control group n=75	0	16	1.1 (2.6)	0 (0-1)	
All Contacts (Health & Social Services)					
Experimental group n=87	0	1643	91.0 (282.3)	23 (0-48)	Exp n=87, Con n=75 p=0.55
Control group n=75	0	944	70.0 (141.6)	26 (8.5-61.5)	

6.4 GP REFERRALS TO OTHER SERVICES

Data on GP referrals to other services were obtained via GP held record cards for a total of 220 clients (114 experimental and 106 control). Only sample 1 data (clients who were interviewed at all three stages) will be presented here. GP held record cards were obtained for 161 out of 162 clients in sample 1. A total of 72 clients (45%) had no referrals made for them by the GP.

Table 24 shows a cross-tabulation and chi-square test, by experimental and control group, for no *referrals* versus *one or more* referrals.

Table 24 Cross-tabulation of no referrals versus one or more referrals by GPs for the experimental and control groups.

Referrals	Experimental group	Control group
None	46 (53%)	26 (35%)
One or more	41 (47%)	48 (65%)
Total	87 (100%)	74 (100%)

Chi-square= 5.09 (1DF) p=0.02

It can be seen from Table 24 that there was a significant difference between the two groups in that the control group was more likely to have had *one or more* referrals made for them. In the sub-sample of clients who had one or more referrals, the number of referrals ranged from 1 to 5. The experimental and control group medians were both 1 but the mean rank for the control group was 49.3 compared with 39.9 in the experimental group (Mann-Whitney U= 777.0, p=0.04). Therefore the control group had a small, but statistically significantly, greater number of referrals made for them to other professionals by the GP than the experimental group. The significant difference between the two groups on number of referrals was also present when Sample 2 was analysed.

On the basis of the above evidence, the null hypothesis that domiciliary physiotherapy made no difference to the number of GP referrals can be rejected. Although the difference is small, the control group had more referrals made for them than the experimental group, and was also more likely to have at least one referral. It would therefore seem that, although domiciliary physiotherapy increased the likelihood of clients having contacts with other services, it also decreased the likelihood of GPs referring clients on to other professionals. In terms of the cost-

effectiveness of the DPS, the saving on GP referrals is probably counter-balanced by the spending on referrals to others by the physiotherapists.

6.5 ADMISSIONS TO RESPITE CARE

Data on admissions to respite care was returned from 114 experimental and 97 control group clients in Sample 2. Overall, 199 clients (94%) had no respite care admissions. Sample 1 data, for the 162 clients who were interviewed at all 3 stages, is presented below. The additional data in Sample 2 did not alter the findings. Table 25 below shows a cross-tabulation, by experimental and control group, for *no admissions* or *one or more* admissions to respite care in sample 1.

Table 25 Cross-tabulation of no admissions versus one or more admissions to respite care for the experimental and control groups

Number of admissions	Experimental group	Control group
None	80 (92%)	70 (93%)
One or more	7 (8%)	5 (7%)
Total	87 (100%)	75 (100%)

Chi-square=0.09 (1DF) p=0.8

Only 12 clients (7% of those who returned their respite care diary sheets and 14% of the 88 clients who said they had a carer) had any admissions to respite care. Respite care was originally devised to prevent those hospital admissions caused by breakdown of carer support (Nolan and Grant 1990). It is therefore surprising that such a small number received what is regarded as an essential service for carers of elderly and disabled people. It can be seen from the above table that there was no significant difference between the experimental and control groups in the proportions of clients who had *one or more than one* episode of respite care. For the sub-sample of clients who had any respite care, the number of episodes ranged from 1 to 7 and respite care was given by local authority nursing homes, district general and peripheral

hospital units and private nursing homes. Respite care admissions did not seem to occur in any regular pattern and the length of any one episode of care ranged from 1 day to 10 weeks.

To further assess any differences between the experimental and control groups, the total length of stay (i.e. the sum of all admissions) was calculated for the sub-sample of clients who received any respite care. Table 26 below shows the minimum, maximum and median values for total length of stay in respite care. The Mann-Whitney U test for small samples (Altman 1991) was chosen, rather than the t-test, to test for differences between the experimental and control groups. The reasons for choosing the Mann-Whitney U test were as follows: the data were not normally distributed; there was unequal variance across the two groups; and, as the Mann-Whitney test is based on ranks rather than means, it would not be affected by an outlying value of 109 days in the control group.

Table 26 Difference between the experimental and control groups on total length of stay in respite care

	minimum (days)	maximum (days)	median (days)
Experimental group n=7	7	27	14
Control group n=5	20	109	30

Mann-Whitney U=2.5 Exact 2-tailed p=0.01

Table 26 shows that there was a statistically significant difference between the two groups. The control group had a greater total length of stay ($p=0.01$), implying that the experimental DPS reduced clients' use of respite care for those who received it. It should be noted that, as for visits to day hospitals mentioned earlier, the sub-sample on which this finding is based is very small ($n=12$). The small size of the sample does not affect statistical conclusion validity, because it is taken account of in the test. However, internal validity, i.e. the causal status of the experimental DPS should be questioned, as the analysis derives from a small post-hoc sub-

group. The small sample size also limits the external validity, i.e. the generalisability of the finding. Therefore there is only tentative evidence on which to reject the null hypothesis that Domiciliary Physiotherapy made no difference to clients length of stay in respite care. The benefits that carers can gain from domiciliary physiotherapy will be discussed in Chapter 5, to explain why domiciliary physiotherapy intervention may reduce carer need for respite care.

6.6 ADMISSIONS TO HOSPITAL

Data on admissions to hospital was returned from 120 experimental and 118 control group clients in sample 2. Overall, 144 clients (61%) had no hospital admissions. Only Sample 1 data will be presented below, as the additional cases in sample 2 did not alter the findings. Table 27 shows a cross-tabulation, by experimental and control group, for *no admissions* or *one or more* admissions to hospital in sample 1.

Table 27 Cross-tabulation of no admissions versus one or more admissions to hospital for the experimental and control groups

Number of admissions	Experimental group	Control group
None	50 (57%)	48 (64%)
One or more	37 (43%)	27 (36%)
Total	87 (100%)	75 (100%)

Chi-square=1.49 (1DF) p=0.2

It can be seen from the above table that there was no significant difference between the experimental and control groups on the proportions of clients who had *no admissions* or *one or more* admissions. Overall, 94 clients (39%) had admissions to hospital, ranging from 1 to 7, over the follow-up period. The length of stay for a single admission ranged from 1 day to 4 months. To further assess any differences between the experimental and control groups, the total length of hospital stay (i.e. the sum of all admissions) was calculated for the sub-sample of clients who had any hospital admissions. Table 28 below shows the minimum, maximum and mean values for total length of hospital stay. The t-test was chosen as the most appropriate

statistical test as the data were normally distributed and there was equal variance across the groups.

Table 28 Difference between the experimental and control groups on total length of hospital stay in days

	minimum	maximum	mean (SD)
Experimental group n=37	1	116	24.2 (28.2)
Control group n=27	1	115	28.5 (29.9)

$t = -0.69$, $p = 0.5$

The above table shows that there was no significant difference between the experimental and control groups in mean length of hospital stay.

7. DISCUSSION OF RESULTS

In this chapter data have been analysed to test the following primary hypotheses:

- I. Domiciliary Physiotherapy will improve level of independence as measured by the Barthel Activities of Daily Living Index.
- II. Domiciliary Physiotherapy will improve health status as measured by the Nottingham Health Profile.
- III. Domiciliary Physiotherapy will reduce use of other health and social services.
- IV. Domiciliary Physiotherapy will reduce the number of GP referrals to other agencies.
- V. Domiciliary Physiotherapy will reduce the number of episodes of respite care and mean length of respite care stay.
- VI. Domiciliary Physiotherapy will reduce the number of hospital admissions and mean length of hospital stay.

This section will aggregate and summarise results relevant to the above hypotheses.

Conclusions will be drawn in the context of possible sources of error associated with the method of service provision, choice of outcome measures, sampling, sample attrition and appropriateness of the research paradigm.

7.1 ACTIVITIES OF DAILY LIVING AND HEALTH STATUS

There were no statistically significant differences between the experimental and control groups, in change of Barthel Index or Nottingham Health Profile scores, at either 3 or 12 months. The null hypotheses for I and II above can not, therefore, be rejected and it must be concluded that, overall, Domiciliary Physiotherapy made no statistically significant difference to clients' level of independence in activities of daily living or health status, as measured by the Barthel Index and Nottingham Health Profile. If the results are taken at face value they indicate that housebound elderly clients with long-term physical disability showed no measurable improvement, either with or without domiciliary intervention. Several possible reasons for the failure to reject the primary null hypotheses relating to level of independence and health status will now be discussed.

The sample was much smaller than anticipated, with only 245 clients recruited instead of the intended 800. As a result, the power of statistical tests to detect a significant difference was greatly reduced. If the planned number of subjects had been recruited, a significant difference between the experimental and control groups might have been detected. For example, the experimental group had an improvement in score on the mobility section of the NHP of 3 points, compared to zero improvement in the control group. This was significant only at the 0.07 level. With a larger sample size, the probability of obtaining this result by chance might have been lowered to below 0.05. Similarly, the experimental group had proportionally more clients who were independent in climbing stairs at 3 months (after the scoring categories in the chi-square test were collapsed to eliminate the problem of low expected frequencies). This

difference was significant at the 0.056 level, which is very close to conventional statistical significance. The finding supports an outcome of the Bradford Stroke Trial (Young and Forster 1992) that home treated patients performed better on stairs than Day Hospital patients.

It is possible that domiciliary physiotherapy could have had real benefits that the chosen outcome measures for level of independence and health status failed to detect. Tightly focused dependent measures may miss changes that they do not encompass. For example, the small amount of qualitative data from clients and carers, which will be presented in Chapter 5, hints that domiciliary physiotherapy may have benefited carers as much as clients. However, the carer perspective was not measured. No specific physiotherapy measures for a generic client population could be found at the time of designing the study. The Barthel Index and the Nottingham Health Profile were selected more for their general applicability to multi-diagnostic client groups than their proven ability to assess the outcome of physiotherapy intervention. The ceiling effect of the Barthel Index has limited the extent to which measurable improvement could be shown for 'better' clients, as the baseline median score was high in the scale. As previously mentioned, the total score of 20 is made up of several items, all with different weightings. In consequence, attributing meaning to small changes of one or two points may be problematic. One point improvement might have a crucial impact on daily life, signifying, for example, that the client could now bathe completely independently after previously needing help from another person. On the other hand, one point could mean only that the client has moved from needing major to minor help from another person in transferring. The implications for future research of the lack of sensitive physiotherapy measures in the field of generic domiciliary practice are discussed in the Discussion Chapter.

Sample attrition was present in both the experimental and control groups. In general, the less independent and more socially isolated clients, perhaps those most likely to improve, were lost

to the trial. Loss of these worst cases may well have reduced the number of clients for whom a measurable treatment-related effect could be demonstrated and thereby contributed to the failure to reject the null hypotheses. On the other hand, it could equally be argued that the more dependent and socially isolated clients could have the most intractable problems. If so, fewer numbers of such clients in the sample would have enhanced the likelihood of rejecting the null hypotheses.

As the control group was not a strict 'no-treatment' group, the extent to which domiciliary physiotherapy might have prevented deterioration could be hidden by the effect of other services. Alternatively, it is possible that domiciliary physiotherapy simply wasn't effective. For example, therapists may have been working within an inappropriate/ineffective model of practice or an insufficient number of treatments may have been given. The possible reasons for 'failure' of the DPS are discussed more fully in the Discussion Chapter. However, on the other hand, the primary hypotheses listed above do not take into account any sub-groups of the client population. It is possible that there may be benefits for definable smaller groups, which are hidden by the results for the larger sample. Exploratory sub-group analyses (according to diagnostic categories) were undertaken after the primary hypotheses had been tested but, possibly due to small sample sizes or lack of sensitivity of generic outcome measures, no notable differences were detected.

Levels of independence and health status were judged only from the clients' perspective. No hypothesis was postulated regarding carer outcomes. The beneficial effects of domiciliary physiotherapy on carers have not been assessed. The small amount of qualitative data obtained from carers, to be presented in Chapter 5, suggests that domiciliary physiotherapy can be beneficial. For example, physiotherapists can improve carers' skills (by teaching easier ways of moving and handling the client), they can give carers emotional support (by reassuring and

explaining), they can liaise between carers and other services (by co-ordinating a common team approach which includes the carer).

The RCT model has the limitations that are inherent in any experimental paradigm.

Standardised outcome scales were chosen in advance. Although they were reliable, and apparently well validated, these measures may not have detected other real changes. Perhaps preliminary qualitative work would have identified the most likely positive effects of domiciliary physiotherapy, which could then have been quantified with specially designed measures rather than 'standard' tools. Further critical review of the experimental research paradigm and recommendations for future research are provided in the final chapter.

7.2 USE OF OTHER HEALTH AND SOCIAL SERVICES

Experimental hypothesis III predicted that domiciliary physiotherapy would reduce clients' use of other services. However, there was evidence to suggest that access to the DPS may have significantly increased, rather than decreased, the proportion of clients having at least one contact with another health or social service. For those clients who did receive other health and social services, there was no difference between the two groups on total number of contacts. It should be noted, however, that GPs made significantly more referrals to other services for the control group, which may balance the finding that the DPS made more referrals for the experimental group.

With regard to contacts with individual services, there was a significant finding related to use of day hospitals. It was found that, for the sub-sample of clients who attended day hospitals, the control group made significantly more visits than the experimental group. This one finding, related to day hospital use, in support of experimental hypothesis III does not provide sufficient evidence to reject the null hypothesis. There is no evidence that, in general, domiciliary physiotherapy reduced clients use of other health and social services. Indeed, in one sense, the

DPS increased use of other services as it acted as a gatekeeper/referral agent and increased clients' likelihood of having at least one contact with another service. Other studies have shown that elderly people in the community receive few services (Allen *et al.* 1992). The role of the DPS in liaising with other agencies and referring clients on was highlighted as a benefit in the client/carer interviews, so perhaps the failure to reject the null hypothesis should not be viewed entirely negatively. Clients/carers valued the teamwork between physiotherapists and nurses and it may be unrealistic as well as undesirable to expect community-based services to work in isolation of each other.

Large numbers of client held data collection diaries were returned with no entries. Fieldworkers made every effort to clarify that the blank sheets truly represented no contacts, rather than failure to make entries. Therefore, it can be assumed that the data were reliable and that there were, indeed, large numbers of clients who had no contacts with any other service.

Consequently the data were skewed and the only way to perform meaningful analyses was to collapse data to a categorical level of *no contacts* and *one or more* contacts and create small sub- samples of clients who did have contacts. The finding that domiciliary physiotherapy reduced clients use of day hospitals should be treated with caution until replicated with larger numbers of subjects. Interestingly, however, a previously mentioned recent study of domiciliary versus day hospital physiotherapy (Young and Forster 1992) came out in favour of the domiciliary method. If domiciliary physiotherapy *is* more effective than day hospital physiotherapy, the tentative finding in this study, that domiciliary physiotherapy reduced clients use of day hospitals, may well be valid.

The RCT may have started with the wrong theory. It seems that domiciliary physiotherapy will *increase*, not *decrease*, clients use of other services, in terms of gaining clients at least one contact with another service. However, it may also result in reduced referrals to other agencies

and reduced use of day hospital and respite care. The possible reasons for the gatekeeper/referral agent role will be explored in the Discussion Chapter.

7.3 GP REFERRALS

Experimental hypothesis IV predicted that domiciliary physiotherapy would reduce the number of GP referrals to other agencies. A small, but statistically significant, difference was found ($p=0.04$), with the control group having more referrals than the experimental group. There was also a significant tendency for the control group to be more likely to have at least one referral ($p=0.02$).

The significant difference between the two groups in number of referrals should be seen in the context of the very small difference obtained. Both groups had a median number of referrals of 1, but the mean rank was higher for the control group. Although the null hypothesis of no difference can be theoretically rejected and it can be stated that domiciliary physiotherapy did reduce number of GP referrals, the reduction was a very small one. It should also be noted that GPs did not always fill in the GP record cards on which the data on referrals were collected. Although the fieldworkers gave regular reminders and checked all clients' medical records retrospectively at the end of the study, the data may not have been totally accurate

7.4 RESPITE CARE AND HOSPITAL ADMISSIONS

Experimental hypotheses V and VI predicted that domiciliary physiotherapy would reduce number of admissions and length of stay in respite and hospital care. With respect to hospital admissions, there was no significant difference between the experimental and control groups in either number of hospital admissions or length of hospital stay. The null hypothesis cannot, therefore, be rejected and it must be concluded that domiciliary physiotherapy made no difference to clients' admissions to hospital or length of hospital stay. With respect to respite care, it was found that there was no evidence of a difference between the two groups on number of episodes of care but, for the sub-sample who received respite care ($n=12$), the control group

had a significantly greater total length of stay than the experimental group. Therefore, although the null hypothesis regarding episodes of respite care can not be rejected, there is provisional evidence to reject the null hypothesis that domiciliary physiotherapy makes no difference to total length of stay in respite care. It may be that domiciliary physiotherapy provides effective carer support, thereby reducing the need for respite care, which is usually provided to support carers. However, as with visits to day hospitals, mentioned earlier, it should not be firmly concluded that domiciliary physiotherapy reduced clients' length of stay in respite care. Multiple exploratory analyses may, by chance, throw up significant findings (Pocock 1985) therefore replication with larger numbers of subjects is required.

8. SUMMARY OF CHAPTER

This results chapter has presented the outcomes of the trial of domiciliary physiotherapy by using quantitative data to test the primary hypotheses. Exploratory analyses with small sub-groups have also been presented. The focus of the next chapter shifts from quantitative outcomes to an analysis of the process of domiciliary physiotherapy.

CHAPTER FIVE

THE PROCESS OF DOMICILIARY PHYSIOTHERAPY

1. OVERVIEW OF CHAPTER

This chapter will present an analysis of the process of domiciliary physiotherapy. Firstly, GPs' diagnosis and reason for referral of clients will be discussed, to give a picture of the perceived physiotherapy needs of clients. Secondly, a quantitative analysis of number of visits and duration of episodes of domiciliary physiotherapy intervention will be presented. Finally, this chapter will discuss domiciliary physiotherapy intervention from a qualitative perspective, by presenting an interpretive analysis of practice. The interpretive analysis draws from insights derived from the researcher's experience, a focus group of experienced therapists and two client/carer interviews.

2. GP DIAGNOSIS AND REASON FOR REFERRAL TO THE TRIAL

The DPS was dependent on GPs for referral of clients. Therefore, before moving on to a discussion of the process of domiciliary physiotherapy, it is important to examine GPs' diagnosis of clients and their reasons for client referral. Diagnostic information and reasons for referral need to be taken into account when planning physiotherapy intervention, as they indicate the GPs' expectations of the DPS. At the point of referral, before randomisation, GPs were asked to fill in a referral form (see Appendix 3). This form asked for the GPs' reason for referral as well as standard information such as client name, address, date of birth, diagnosis and current medication.

2.1 DIAGNOSIS OF CLIENTS REFERRED TO THE TRIAL

It is usual for physiotherapists to require a doctor's diagnosis, so that they can take it into consideration when assessing a client's problems and planning interventions. For example, a diagnosis of heart disease would alert a physiotherapist to the possible dangers to the client of

unaccustomed exercise/activity. GPs provided at least one diagnosis for 205 (92%) of the 222 clients interviewed at the first stage. In the remaining cases, GPs failed to fill in referral forms. Where more than one diagnosis was given, the fieldworkers asked the physiotherapist responsible for the client to indicate the main diagnosis relevant to the referral for physiotherapy. For each client, the main diagnosis was then classified according to the three digit codes of the International Classification of Diseases (World Health Organisation 1977) and then re-coded into four diagnostic groupings: neurological problems, orthopaedic/rheumatological problems, respiratory problems and other problems. These groupings were chosen to allow comparison with other studies (Frazer 1980, Sheffield Health Authority 1982, Smyth 1985) which used similar systems for categorising patients. Diagnoses of all clients recruited to the trial have been previously discussed, in Chapter Three, and it was found that there were no significant differences between the experimental and control groups with respect to diagnostic group. In this chapter the diagnoses of clients randomised to the experimental group for treatment by the DPS will be considered in more detail, to provide a profile of those who were given domiciliary physiotherapy intervention. Diagnoses were given for 110 (96%) of experimental clients and are shown in Table 29 overleaf. Clients who subsequently dropped out are not excluded from this table as the intention is to present a profile of all those referred.

Table 29 Main diagnoses of clients randomised to the experimental group (n=114)

Diagnostic grouping	Number (%) of clients
Neurological problems, e.g. stroke, multiple sclerosis, motor neurone disease, Parkinson's disease	39 (34%)
Orthopaedic/rheumatological problems, e.g. rheumatoid arthritis, osteoarthritis, fractures	35 (31%)
Respiratory problems, e.g. chronic obstructive pulmonary disease, bronchiectasis, lung cancer	30 (26%)
Other problems, e.g. heart/vascular disease, non specific mobility problems, skin ulcers	6 (5%)
No diagnosis given	4 (4%)
Total	114 (100%)

The DPS received referrals mainly for clients with long-term chronic conditions such as stroke, arthritis and respiratory disease. Clients were either in an acute exacerbation phase of a chronic condition (e.g. rheumatoid arthritis or chronic obstructive pulmonary disease) or struggling to cope with the long term problems associated with residual disability/handicap from conditions such as stroke. Some clients were referred in the terminal stages of respiratory or neurological disease. The extent to which clients referred to this RCT were representative of those referred to other domiciliary physiotherapy services has already been considered in Chapter Three, where comparisons were made on a range of variables including diagnosis. For the purposes of this present chapter it is relevant to note that the diagnoses of clients referred were very similar to those reported in other studies of domiciliary physiotherapy services (Frazer 1980, Sheffield Health Authority 1982, Smyth 1985).

The DPS physiotherapists had previous hospital-based experience of treating patients in the acute stages of these conditions, but they were not experienced in home-based treatment for individuals in the later chronic stages. It took time for them to fully develop their role with

clients and carers. The relationship between physiotherapists' previous experience and the emergent model of physiotherapy practice is considered later in this chapter.

2.2 REASON FOR REFERRAL OF CLIENTS TO THE TRIAL

GPs were asked to state their reason for referral to the DPS separately from the client's diagnosis. A reason for referral was given in 114 (100%) of cases in the experimental group. Reasons for referral were grouped under five main headings, as shown below in Table 30.

Table 30 Reason for referral of clients in the experimental group (n=114)

Reason for referral	Number (%)
Signs/symptoms of the disease, e.g. <i>balance impairment, poor gait, spastic hemiplegia, muscle weakness, poor mobility, chest infection, shortness of breath.</i>	89 (78%)
Inability of the client to travel for out patient physiotherapy, e.g. <i>unable to leave the house, too frail to travel by ambulance.</i>	8 (7%)
Request for pain relief or pain management for problems not necessarily related to the main diagnosis, e.g. <i>back ache, neck pain, aching joints.</i>	7 (6%)
Problems associated with ageing/general frailty, e.g. <i>at risk from falls, gone off legs, loss of confidence in walking.</i>	6 (5%)
Request for a specific function, e.g. <i>teach client/carer how to transfer, assess on stairs, teach carer how to lift client, advise on prevention of further problems, remove secretions, teach breathing exercises.</i>	4 (4%)
Total	114 (100%)

In 89 cases (78%), the reason for referral was specifically related to the signs/symptoms of the disease given as the diagnosis. For example, reasons for referral such as *balance impairment, poor gait, spastic hemiplegia* were given for clients with neurological diagnoses; *muscle weakness, poor mobility* for clients with orthopaedic/rheumatological diagnoses; and *chest infection, shortness of breath* for clients with respiratory diagnoses. However, in 25 cases (22%), reasons for referral were not linked to the diagnosis. For 8 clients (7%), reasons for referral were related to the inability of the client to travel for out patient physiotherapy, e.g. *unable to leave the house, too frail to travel by ambulance*. For 7 clients (6%), the GP requested pain relief or pain management for problems not necessarily related to the main diagnosis, e.g. *backache, neck pain, aching joints*. In 6 cases (5%), problems associated with

ageing/general frailty were given as reasons for referral, e.g. *at risk from falls, gone off legs, loss of confidence in walking*. For 4 clients (4%), the GP asked the physiotherapist to fulfil a specific function/role, e.g. *teach transfers, assess on stairs, teach carer how to lift client, advise on prevention of further problems, remove secretions, teach breathing exercises*.

In the early stages of the trial, reasons for referral were often the ones related to the signs and symptoms of the disease/diagnosis, suggesting that GPs may not have felt able to request specific physiotherapy services. As the trial progressed, and physiotherapists began to develop working relationships with GPs, reasons for referral became more linked to specific physiotherapy functions than the diagnosis of the client. In some cases, the GP would follow up the referral form with a further telephone call to explain the problem more clearly and ask for the physiotherapist's initial impression on whether their input would be beneficial. Thus, as the research progressed, experiences generated by the trial itself influenced the relationship between the GPs and physiotherapists. Any change in the nature of GP referrals to the DPS could have subtly influenced outcome by shifting the emphasis of intervention. The methodology of pragmatic trials includes service development as a key feature, yet such developments are often overlooked when outcomes are reported.

Throughout the trial, both in the pilot and the randomisation phase, the team tried to educate GPs on the role of domiciliary physiotherapy in order to maximise appropriate referrals. They made a visit to each practice during the pilot phase to talk to GPs about the trial and the experimental domiciliary physiotherapy service. They explained how the GPs should refer to the trial, and discussed what were the most suitable types of referral. After each episode of care, the physiotherapist sent the GP a discharge letter, outlining the intervention that had been given and the outcome for the client. On many occasions, physiotherapists also used the telephone to update the GP on a client's progress, or notify him/her of a sudden change in the client's condition. Some GPs were very keen to learn more about the DPS. They welcomed the

physiotherapists into their team meetings and communicated with them about individual clients' progress. Others treated the DPS like any other secondary service and made no contact after the initial referral form, thus limiting their opportunities to learn about the role of domiciliary physiotherapy. GPs who were present at the initial practice visit and who were willing to communicate with the physiotherapist on a regular basis had a better opportunity to gain insight into how physiotherapy was addressing their patients' problems. It became apparent that investing time and effort in communicating with GPs reaped rewards, in many cases, of increased number and suitability of referrals. Where communication from the GP was limited, referrals were rare and not always appropriate.

In general, most GPs who referred to the trial had a basic awareness of the types of conditions/diagnoses potentially requiring physiotherapy and were able to highlight specific signs and symptoms amenable to physiotherapy intervention. Some GPs eventually developed an enhanced awareness and could anticipate the need for a particular physiotherapy function, regardless of the diagnosis. It seemed that the GPs who developed a better understanding were more receptive to educational messages, more willing to communicate about individual clients' progress and regarded the physiotherapist as a part of the primary health care team. A lesson learned from the trial was that a GP could not always take on the role of gatekeeper for physiotherapy services without guidance. Continuous education and feedback is essential to promote good referral practice. Informal mechanisms of communication such as telephone calls about individual clients and team meetings seemed to be effective.

3. THE PROCESS OF DOMICILIARY PHYSIOTHERAPY: A QUANTITATIVE ANALYSIS OF NUMBER OF VISITS AND EPISODES OF PHYSIOTHERAPY INTERVENTION

All clients were seen by a physiotherapist within a week of randomisation to the experimental group. Referrals were seen the same or the next day for urgent problems, such as a new stroke or chest infection. The client was assessed and then treated as appropriate. In keeping with

usual patterns of work for physiotherapists, visits were normally made between the hours of nine and five. Occasionally, at the discretion of the physiotherapist, an evening or weekend visit was made. New referrals were not accepted on Saturdays or Sundays.

3.1 EPISODES OF INTERVENTION

The concept of an episode of physiotherapy intervention has been used to provide a quantitative analysis of the process of physiotherapy. In this context, an episode represents the physiotherapy intervention given to a client, via a series of visits, over a period of time until the client was discharged. The number and frequency of visits was entirely at the discretion of the physiotherapist and the episode of intervention normally ended when the physiotherapist discharged the client. Length of episodes was not prescribed in advance so that the intervention could be tailored to the needs of the individual. The decision to discharge was likely to be influenced by several variables. In the main, clients were discharged when the physiotherapist judged that they had reached their full potential or when original goals for treatment had been reached. Other issues, such as the client's demands for treatment, or dependency on physiotherapy, may have also led to some episodes becoming longer than others. At a pragmatic level, even the size and demands of the physiotherapist's caseload may have influenced decisions on when to discharge clients. In order to offer flexible service provision, clients were allowed to re-refer themselves, or the GP could request a re-assessment if problems recurred after discharge. A re-referral (whether by the client or the GP) was counted as a new episode of DPS intervention for experimental group cases. It should be noted that experimental group clients were not randomised again if re-referred. The number of episodes of treatment received by clients is shown in Table 31 overleaf.

Table 31 Number of episodes of physiotherapy intervention in the experimental group (n=114)

Number of episodes	Number (%) of clients
1	99 (87%)
2	13 (11%)
3	1 (1%)
4	1 (1%)
Total	114 (100%)

Table 31 shows that the majority of clients (87%) received only one episode of intervention, although the length of episodes was variable (see 3.2. below). A total of 13 clients (8 male and 5 female) received 2 episodes of intervention. They were aged between 46 and 91 (mean age 69) and were diagnosed with stroke (n=6), other neurological problem (n=3), respiratory problem (n=2) and arthritis (n=2). The client who received 3 episodes of care was a 67 year old male who lived with his carer. He had chronic respiratory disease and his three episodes were short intensive courses of treatment for acute chest infections. The maximum of 4 episodes of care was received by a 64 year old female who lived alone with no carer. She had suffered a stroke and had an initial long intensive course of treatment (26 visits over 23 weeks), followed by 2 follow up courses (4 visits over 7 weeks and 4 visits over 5 weeks). The fourth episode consisted of 2 planned reassessment visits over a 16 week period.

3.2 NUMBER OF VISITS PER EPISODE OF PHYSIOTHERAPY INTERVENTION

The duration of an episode was measured in whole weeks and the total number of visits was counted for each episode. The median duration of the first episode was 12 weeks (range 1 - 78 weeks, inter-quartile range 3-28 weeks), over which a median of 12 visits was made (range 1 - 96 visits, inter-quartile range 5-20 visits). In a survey of a domiciliary stroke rehabilitation service (Gladman *et al.* 1995), the overall median length of 'contact' with patients was 10 weeks over which a median of 6 rehabilitation visits (occupational therapy and physiotherapy) were made. However, sub-group analysis revealed that only patients discharged into the

domiciliary service from stroke units (compared with those discharged from care of the elderly wards or general medical wards) achieved a statistically significant improvement (Gladman *et al.* 1995). These patients had a long median contact period of 6 months, over which a median of 18 visits was made. After Gladman *et al.* (1995) compared the results of their RCT of hospital based and domiciliary rehabilitation for stroke patients discharged from hospital with those of the Bradford Community Stroke Trial (Young and Forster 1992), they concluded that between 15-20 visits in six months are needed to obtain measurable benefits, and that lesser amounts of therapy are either ineffective or produce effects too small to be detected.

The earliest RCT of physiotherapy (Smith *et al.* 1981) which, again, looked at therapy after stroke, also found that improvement was greatest in those who received intensive treatment. The possible theory of *more treatment = more improvement* should be applied to the DPS trial with caution, given that the evidence for the dose-related effect comes entirely from the literature on stroke rehabilitation. Also, although correlations between amount of treatment and level of improvement are informative they do not necessarily provide evidence of treatment effectiveness, as those given more or less treatment in the studies cited above were not selected at random. For example, therapists may have given the most 'promising' cases more attention, thereby producing a spurious dose-related effect. In the DPS trial 45 clients (39%) received the 15 or more visits recommended by Gladman *et al.* (1995). When these clients were compared with those who had less than 15 visits (n=69) there were no significant differences in their NHP scores at 3 or 12 months. However, there was a significant difference between those with 15 or more visits and those with less than 15 visits on their Barthel change score at 12 months (p=0.02). The clients who had less than 15 visits had the greatest improvement (median difference 1 point). Correlational analysis also revealed a weak, but significant, negative correlation (Spearman $r = -0.28$, $p=0.01$) between number of visits and improvement on the Barthel at 12 months, suggesting that more visits were made to those who deteriorated. These findings conflict with those of other studies (Smith *et al.* 1981, Gladman *et al.* 1995) but do not

suggest that more domiciliary physiotherapy leads to client deterioration. The DPS therapists may have continued to offer intervention even when the client's condition could not be improved. The negative correlation between number of visits and improvement on the Barthel scale may thus have been produced by domiciliary physiotherapists prolonging episodes of treatment for clients with deteriorating conditions.

4. THE PROCESS OF DOMICILIARY PHYSIOTHERAPY: AN INTERPRETIVE ACCOUNT OF PRACTICE

The difference between domiciliary and hospital-based physiotherapy is often defined purely in terms of the switch from the clinical to the community setting. However, practicing physiotherapy in someone's home, rather than in a hospital/clinic, involves more than just a change of environment. In this section, the process of domiciliary physiotherapy offered in the trial will be analysed in order to make some important distinctions between mainstream and community based practice. As the analysis is grounded in the author's personal and experiential knowledge, parts of the following text will be written in a reflective style in the first person.

4.1 BACKGROUND AND CONTEXT

At the time of the trial, domiciliary physiotherapy was still a relatively new and emerging discipline in the UK. Only one part-time physiotherapist in the team had previously worked in the domiciliary field. The others came to the DPS from hospital based services. A period of development was built into the project, during which the DPS operated without randomisation for 4 months. In this period the physiotherapists treated 299 clients referred from GPs and other primary health care team members. The purpose of the development phase was to allow for piloting of the service so that an agreed service profile could be drawn up before the start of the trial. By the time the trial began, the physiotherapy team had developed a shared understanding on issues such as how to prioritise referrals, who was responsible for each geographical area of the City, and what were to be the minimum standards for record keeping (see Chapter Two, Methods). Standardising other elements of practice, such as the model, philosophy and bases

for clinical decision making was less straightforward. The interpretive account of the process of domiciliary physiotherapy will discuss the apparent transition that the team made from a medical to a more client-centred model of practice. Their initial approach of making clinical decisions on the basis of signs and symptoms shifted to a philosophy of client and carer empowerment within which the client/carers perspective influenced the choice of treatment.

4.2 METHOD OF DATA ANALYSIS

Data obtained from two client/carers interviews and a focus group discussion with six therapists not involved in the trial have been integrated with my experiential observations and reflections made during the trial, to construct an interpretive account of the process of domiciliary physiotherapy. An interpretive account is one that takes into consideration multiple perspectives to explain the meaning of sequences of events and patterns of behaviour (Stringer 1996). Qualitative data from the client/carers interviews and the focus group were analysed using thematic analysis, where each data source was considered deductively (with questions or themes in mind), and inductively (with no preconceived ideas about what the data would reveal). The analytical aim was to open up the 'black box' of domiciliary physiotherapy, not to make strong generalisations about its practice.

4.3 EXPERIENTIAL KNOWLEDGE AS A SOURCE OF DATA

As service manager, I led weekly team meetings and participated in all decisions that were made concerning the continuing development of the DPS. Whether my participation in decision making is seen as advantageous or disadvantageous depends on the perspective from which the issue is viewed. In a positivist experimental paradigm, the researcher should remain distanced from the research setting to promote objectivity and minimise bias (Bryman 1988). However, as manager (as well as researcher), I could not adopt a distanced or neutral perspective.

Throughout the study, my own values and opinions as an experienced domiciliary physiotherapist necessarily influenced the development of the service. From an interactionist perspective, my personal experience and participation would be viewed as an advantage, giving

insight and theoretical sensitivity to my interpretations (Silverman 1993, Ely *et al.* 1994, Miles and Huberman 1994). Experiential knowledge and personal insight as a source of 'data' has been previously discussed in Chapter Two (Methods). Such insight, often disregarded in trials, may provide a basis upon which a deeper understanding of domiciliary physiotherapy can be built (Higgs and Titchen 1995, Parry 1997).

4.4 INTERVIEWS WITH CLIENTS AND CARERS

Semi-structured interviews were conducted with two clients and their spouse carers to gain an insight into client and carer perceptions of the role and value of domiciliary physiotherapy. After the RCT was completed the DPS staff were asked, as key informants, to nominate clients and carers who had experienced regular domiciliary physiotherapy alongside at least one other community based service.

The first client was a 70 year old man with progressive multiple sclerosis (MS), mainly affecting his lower limbs. He was diagnosed 10 years previously and lived with his wife. They received care at home from the following services: GP, district nurse, home help, social services occupational therapist and domiciliary physiotherapist. As they declined to be taped, the interview was recorded by means of observational notes. The second client was a 69 year old man with a history of multiple strokes leading to a right sided hemiplegia and expressive communication problems. He lived with his wife and they received care at home from the following services: GP, district nurse, home help, care assistant and domiciliary physiotherapist. The client was present at the interview but not able to talk at length. He listened to the conversation, gave short verbal responses, and made non-verbal gestures to indicate his agreement or disagreement with his wife's opinions. This interview was taped and transcribed.

The client and carer were interviewed together and both were encouraged to answer questions and participate in discussion. I presented myself as a researcher, not a physiotherapist, in order to appear 'neutral'. Both interviews were conducted in the clients' own homes, at a time to suit them, and each lasted approximately one hour. The intended interview style was conversational, and the following broad topics were discussed: the role and function of the DPS and its impact on the client's level of independence and health status; and the value of the DPS, both on its own, and as part of a wider primary health care team.

Interview transcripts, observational notes and theoretical notes were initially analysed in a deductive manner, in the light of the experimental hypotheses stated at the beginning of this chapter. Data were then analysed from an inductive perspective with no preconceived questions or theories in mind. The initial deductive focus for data analysis was the impact of the DPS in relation to the pre-determined outcomes of level of independence and health status. A full description of how themes and categories were developed was given in Chapter Two (Methods). Two themes were constructed: *Improving clients' level of independence* and *Improving clients' level of health status*. Three further themes emerged from inductive analyses: *Providing emotional support for clients and carers*, *Liaison with other agencies* and *Perspectives on receiving physiotherapy and other services at home*. Categories within each of the themes are set out overleaf.

Theme: *Improving clients' level of independence*

Categories: Hands-on physiotherapeutic intervention
Teaching the client and carer new skills

Theme: *Improving clients' level of health status*

Categories: Giving general advice and information
The relationship between the client and the physiotherapist

Theme: *Providing emotional support for clients and carers*

Categories: Counselling
Faith and reassurance

Theme: *Liaison with other agencies*

Categories: Communication between agencies
Inter-agency referrals

Theme: *Perspectives on receiving physiotherapy and other services at home*

Categories: Value and benefits
Drawbacks

4.4.1 Improving clients' level of independence

Both interviews yielded information relating to how carers and clients perceived the role of domiciliary physiotherapy in improving the client's level of independence. Two main categories emerged, relating to hands-on therapeutic intervention and teaching the client and carer new skills.

Hands-on physiotherapeutic intervention

The perceived value of direct hands-on physiotherapy was discussed in both interviews. The carer of the stroke client had expected physiotherapy to consist of an exercise routine and she was sceptical about its potential value to her husband:

I thought it would be exercising and that kind of thing and I couldn't myself see how they could do a lot with exercising.

However, she later realised that physiotherapy involved much more than exercise, and came to value the effect physiotherapy had on her husband's mobility:

But the way it's been going on it's more or less talking, explaining and then doing the job. You know, sort of coaxing him to get up, to stand up, and then, holding hands, sort of saying now put this foot forward and this one. And then it's gradually got that he knows he's got to get those feet going and he is doing it and it's working marvellous. With her help we're getting him on his feet slowly but surely. He couldn't put one foot to the ground a few weeks ago, but now, with help, he's coming onto his feet.

The MS client told of a different experience where the physiotherapist had tried an exercise therapy approach but, in his words, *my legs were no good*. He felt he had been helped more by the physiotherapist teaching his wife and the district nurses different ways to move and handle him (discussed more fully under *Teaching client and carer new skills* below).

Teaching the client and carer new skills

Domiciliary physiotherapists teach the most appropriate way for others to move and handle clients who can not move themselves. They also teach the most immediate carer therapeutic skills if appropriate. The MS client had been experiencing significant distress and discomfort while being moved and handled. He talked of how the physiotherapist had taught his wife and the district nurses new and more efficient ways to handle and move him in and out of chairs and the bed. The new handling methods involved a long, but comfortable, series of transfers from bed to wheelchair to stair lift to chair, to get him downstairs in the morning and back upstairs at night. The client viewed being able to come downstairs for the day as *getting back to normal*.

The carer of the stroke client had already begun to rethink her own role, in the light of the physiotherapist's teaching. She knew that her husband might not maintain his improvement once physiotherapy ended, but she saw herself as having acquired the skill to help him continue his progress:

He may forget their faces, but he'll not forget what to do, what they told him to do. You see I will take over and I will do exactly the same as what they have done, because I know what they've done is the right thing.

4.4.2 Improving clients' level of health status

Domiciliary physiotherapy was seen to benefit clients' health status through physiotherapists giving general advice/information and through the therapeutic effects of the client-therapist relationship.

Giving general advice and information

The carer of the MS client felt that the physiotherapist had considered everything possible to help her husband. Although physiotherapy had not improved the client's own physical mobility, his level of comfort had been improved. The physiotherapist had given them valuable advice on chair cushions and had taken them to an equipment centre to look at hoists for the bathroom to enable him to have a proper bath.

The relationship between the client and the physiotherapist

When talking about other ways in which her husband had benefited from physiotherapy, the carer of the stroke patient mentioned the change in his mood and self-confidence once he had got to know the physiotherapist and become friends with her:

He can't speak very well, but he'll give her the odd word and he'll smile and he'll laugh with her, which of course at first he didn't do. In his way I'm sure he's more confident, although he cannot speak or explain it to you ... It's the way she talks to you, the way she explains things and her attitude. She's a person that speaks to you. She means what she says but she says it with a, what can I say, with a smile kind of thing. She doesn't talk to you as if she's ordering you to do a thing.

4.4.3 Providing emotional support for clients and carers

Both clients and carers obtained emotional support from their contact with the DPS. Categories within the theme of emotional support were counselling, faith and reassurance.

Counselling

The client with MS reflected on how he had come to terms with his disability. Before meeting the physiotherapist, he had *clung onto hope that he would one day get better*. The physiotherapist had spent time listening to him and discussing with him the nature of his problem and he came to realise his illness could not be cured. Once he had come to terms with his disability he acknowledged the value of her advice and interventions to help make his life easier. He compared her approach with that of social services staff, who had suggested *unrealistic solutions* (such as installing a downstairs toilet, which they had already done with their own money) which felt like a *slap in the face*.

Faith and reassurance

The carer of the stroke client talked a lot about what the physiotherapist had done for her and stressed how valuable it had been to feel supported by someone she had faith in:

Well actually, I mean physically she doesn't do anything for me, but mentally she does a lot, because I have great faith in her, I really have. The way she talks to him and explains things to me, like "now this is what I'm trying to do for him" and different things like that. I have faith in her, great faith in her.

Similarly, the carer of the client with MS felt reassured that she was now moving and handling her husband in a correct way that wouldn't hurt him. She valued the physiotherapist's positive feedback on her newly acquired skill and felt she could call on her, at any time, for advice and support.

4.4.4 Liaison with other agencies

Clients and carers valued the links between the DPS and other agencies, in terms of communication and inter-agency referrals.

Communication between agencies

The client with MS made a point of commenting that the communication between the physiotherapist and the district nurses was excellent. Both he and his wife were amazed that the physiotherapist put herself out to meet all the nurses involved, often at unsociable hours, to teach them the correct/best way to move and handle him.

Inter-agency referrals

The second carer remembered that without interagency referral patterns between the nursing and physiotherapy service they would never have had access to the DPS:

It was the nurse who got in touch with the physiotherapist, and they've arranged things between them. They sort of work together and it's turned out all right.

4.4.5 Perspectives on receiving physiotherapy and other services at home

Issues were raised in both interviews regarding the pros and cons of receiving home-based services. Values and benefits were expressed, but these advantages were tempered by some significant drawbacks, as discussed below:

Value and benefits

The client with MS and his carer felt that having services at home enabled them to cope on a day-to-day basis. They saw home-based services as preferable to going to hospital. The client had once spent 3 months in hospital and felt worse when he came out because his bottom was very sore. He had recently made the decision to stop attending the hospital consultant's clinic as he was never in the office more than 4 minutes, it was difficult and stressful to get there and *they weren't doing anything for me anyway.*

The second carer of the stroke client acknowledged the value of the services she and her husband had received:

My husband was very ill when he came out of hospital and without their help I couldn't have carried on. He [the consultant] said that he's getting all the treatment he could get. I don't think he could get more or better treatment [in hospital].

However, she also felt there were distinct drawbacks (discussed below) to having professionals in her home.

Drawbacks

Although she was grateful for all the services her husband had received, the second carer felt there were problems for her in having multidisciplinary home care. She felt as if her home was not her own any more:

Well, to be honest, it has been a bit to cope with having all these people, you know, coming in. But I've come to the conclusion that it just has to be and therefore I appreciate it very very much ... I know it's difficult, but I just haven't felt as if I have got a home, you know? My home is not my own and that's just it.

4.4.6 Summary of client and carer interviews

The perspectives of clients and carers, presented above, are intended to enhance the previous quantitative results and shed a little light on potential beneficial effects of domiciliary physiotherapy which have not been measured. Overall, the clients and carers interviewed valued the DPS in various ways and both physical and emotional benefits were gained. The physiotherapists were perceived not only as hands-on therapists but also as advisors and counsellors. Two clients and their carers represent a very small sample and it is not intended to generalise from their views. The extent to which qualitative perspectives could inform a future study of domiciliary physiotherapy is discussed in the final chapter.

4.5 FOCUS GROUP OF EXPERIENCED THERAPISTS

In order to broaden my own impressions of the challenges of domiciliary physiotherapy, I thought it necessary to investigate whether or not the conflicts and critical issues I perceived within the DPS were the same as those experienced by community based therapy practitioners not involved in the trial. A convenience sample of six experienced community physiotherapists and occupational therapists, attending a part-time degree course at the University of Northumbria, were asked to take part in a focus group discussion about their practice. The focus group was conducted during a two-hour session in the participants' part-time course. We discussed their early experiences as community-based practitioners, how they coped with

difficult/challenging cases and their view of themselves now as experienced practitioners. I obtained their permission to audiotape the session. The focus group discussion was transcribed, and content analysis revealed the following themes and underlying categories:

Theme: *The role of community based occupational therapy/physiotherapy*

Categories: Community based therapy requires an extension of hospital-based practice.
Models of practice need to be broad and flexible.

Theme: *Core knowledge underpinning therapy practice in the community*

Categories: Biomedical knowledge alone is inadequate.
Knowledge gained through experience is invaluable in community practice.

Theme: *Skills needed to be an effective community-based therapist*

Categories: Communication skills are as important as physical treatment skills.
Reflection and self-awareness are key skills.

Theme: *Attitudes and values associated with community therapy practice*

Categories: Client and carer perspectives must be valued.
Teamwork is crucial to the success of intervention.
Therapists must be prepared to re-define their own role in the context of community-based practice.

The focus group data will be presented in the next section, integrated within the interpretive account of the process of domiciliary physiotherapy.

4.6 OVERVIEW OF THE INTERPRETIVE ACCOUNT OF DOMICILIARY PHYSIOTHERAPY PRACTICE

I developed a framework, based on observation during the trial, to illustrate how physiotherapists moved through various phases in their practice before becoming fully adapted to their role. In this interpretive account the early months in domiciliary practice are referred to as the *transitional phase*, which was followed by an interim *settling in phase*, and finally, the

emergent phase, during which the domiciliary physiotherapists became confident and assured.

Various categories emerged within each phase:

The transitional phase

- Categories:
- The challenges of an unfamiliar environment.
 - Coping with an inadequate knowledge base.
 - Developing strategies to cope with unfamiliar problems.
 - Evaluating previous models of practice.
 - Losing power and redefining roles.

The settling in phase

- Categories:
- Extending the scope of physiotherapy practice.
 - Acknowledging the needs of carers.
 - Developing multidisciplinary teamwork.

The emergent phase

- Categories:
- Using negotiation and communication skills.
 - Seeing the client and carer as active participants in physiotherapy intervention.
 - Redefining goals for physiotherapy intervention.
 - Using intuition and experience to create new knowledge.

Themes and categories from the focus group analysis have been integrated into the analysis of phases. For example, the focus group theme *core knowledge underpinning therapy practice in the community* figures in the transitional and emergent phases. In the transitional phase, there was a recognition by the DPS therapists that they were having to cope with an inadequate knowledge base, which maps onto the category from the focus group analysis *biomedical knowledge alone is inadequate*. In the emergent phase, the DPS therapists began to use intuition and experience to create new knowledge, reflecting the focus group category *knowledge gained through experience is invaluable in community practice*. Verbatim quotes from the focus group are used in each phase to validate the interpretive analysis. Some quotes from the client/carer

interviews, previously presented in 4.4 above, are re-stated in the interpretive account, in order to explicitly relate the client or carer perspective to the phase of domiciliary physiotherapy being discussed. It should be noted that these hypothesised phases refer to 'ideal types' only. Different therapists moved through the phases at different speeds, and the development of individual physiotherapists as they encountered 'the community' varied considerably.

4.7 THE TRANSITIONAL PHASE OF DOMICILIARY PHYSIOTHERAPY PRACTICE

4.7.1 The challenges of an unfamiliar environment

The physiotherapists in the RCT were experienced senior therapists, but their experience was largely confined to hospital-based contexts. During transition, the 'new' domiciliary physiotherapists were observed trying to cope with the challenges of an unfamiliar environment. The anxiety associated with moving into the community is illustrated by the following quotes from the focus group. One therapist felt threatened when going into clients' homes:

I used to be frightened of going into someone's house, not knowing what to expect when you get there (focus group participant 3).

Another described how unprepared she felt when she first moved into the community:

What I was completely unprepared for was the context in which I'm working as a therapist (focus group participant 2).

For one person, the early days in domiciliary practice were very stressful:

I floundered entirely at first (focus group participant 1).

4.7.2 Coping with an inadequate knowledge base

In the new unfamiliar community environment, previous clinical biomedical knowledge was not always sufficient. The interpretation of a client's problems within the context of their home life demanded of the DPS physiotherapists an awareness of psychosocial, cultural and behavioural components of disability, which are often hidden in institutional environments. For example, in

a case from the trial, a frail elderly client could not reach her full potential because her daughter was preventing her from getting out of her chair. From the daughter's perspective, the risks to her mother from falling outweighed any potential benefits of independent mobility. The management of this case required the physiotherapist to enter into careful negotiation with the daughter before embarking on any direct intervention with the client. Such dilemmas of risk versus autonomy meant that the DPS physiotherapists had to learn to re-frame clients' problems in a wider context. A participant in the focus group pointed out the weaknesses of her pre-registration training in helping her to cope with work in the community:

Physio training is lacking in the psychological area and we have to develop afterwards (focus group participant 2).

4.7.3 Developing strategies to cope with unfamiliar problems

All the DPS staff had reached a level beyond that of 'novice practitioner' before joining the team. As experienced therapists, they probably used pattern recognition as their main method of clinical reasoning (Higgs and Jones 1995). Pattern recognition involves fast, economical reasoning based on recognising a set of signs and symptom seen before, predicting the outcome of various treatments and selecting treatment based on previous experiences of success. However, in their new situation, they may have been confronted with problems they had not encountered before. For example, a hospital-based therapist, used to treating only patients with acute conditions, would be unfamiliar with the long-term consequences of multiple permanently stiff joints in someone with burnt-out rheumatoid arthritis. Uncertainty in the clinical field may require the practitioner to revert to methods of reasoning more associated with the novice practitioner, such as the hypothetico-deductive model, which they were taught as students. The hypothetico-deductive model involves formulation of hypotheses based on clinical data and testing of these hypotheses through further investigation (Higgs and Jones 1995). In order to cope with unfamiliar problems, the DPS staff tried various approaches to treatment, observed the results, and then reformulated their assessment when the outcomes

were not satisfactory. In team meetings, they frequently discussed with each other ideas for client treatment and they became much more open to trying out different methods. For example, effective strategies used by clients and carers for the self-management of chronic pain were passed on to other team members. As explained by an experienced domiciliary physiotherapist in the focus group:

We all know that nobody's a textbook client. They always come up with a further problem that you can't automatically solve with the therapy that you're using. So you look around from elsewhere. Maybe I'll try that, maybe it'll work, maybe it won't. I think you have to try to get results if you can ... It's too blinkered to use one approach all the time for everybody, particularly if you're tailoring the therapy to the individual (focus group participant 1).

4.7.4 Evaluating previous models of practice

The DPS physiotherapists were all socialised into the medical model in their pre-registration training, and their practice was largely underpinned by biomedical knowledge. The medical model has, at its core, the aim to cure or restore to normal (Roberts 1994). An impairment such as muscle weakness or spasticity will be named as the problem, instead of the loss of functional ability resulting from that impairment (Sim 1990, Roberts 1994). The focus on bodies instead of people has its origins in nineteenth century medicine, when illness was conceptualised as belonging only to the interior of the body. Foucault described the effect of what he called *le regard* or 'the gaze' of the medical profession. Physicians believed that the true nature of the disease could only be learned at post-mortem when the body could be dissected (Foucault 1976). Where the practitioner has curative or restorative goals for treatment, the medical model successfully underpins physiotherapy, e.g. in surgical or acute musculoskeletal areas. However, for clients with permanent disability who were referred to the DPS, the medical model offered a narrow perspective. Reflecting on her early days in the community, an experienced physiotherapist in the focus group remarked:

When I first started my experience was all very physical, my training was physical.

Now I feel as if I've borrowed theories from other disciplines

(focus group participant 2).

Specialist practitioners may tend to see a client's problem only from their own particular perspective and may seek to interpret that problem solely in terms of their own unique past experiences. In his analysis of the reflective practitioner, Schon (1991) suggests that professionals have a unique way of seeing or framing a problem, which then highly influences their course of action to solve the problem. In community care, the practitioner must think laterally to find a way of dealing with clients' problems. Early on in the trial the DPS staff sometimes found it difficult to recognise how someone with an incurable or terminal problem could be helped by their intervention. They did not always see the value of 'hands-off' intervention, such as education, advice or carer support, as an effective alternative to physical treatment.

From my experience as a domiciliary physiotherapist, I was already aware of the inadequacy of the medical model in community based practice and I worked from the assumption that the DPS team would need guidance to help them cope. In my early days in the community, I had often felt isolated and overwhelmed by the scope of my work until I developed links and networks with other professionals. If the experimental intervention was to have an impact on the dependent measures of functional ability and quality of life it was essential that the scope of practice of the DPS team should be extended beyond the medical model, to allow them to cope with unfamiliar problems. I therefore organised an induction programme, where community based professionals from nursing, social work, general practice, social services, residential care homes, occupational therapy, speech therapy and chiropody came along to meet the team and discuss their roles. By raising their awareness of the roles of others, and providing opportunities for staff to reflect on their own new role, I hoped to foster in the DPS staff a positive attitude towards wider models of practice.

4.7.5 Losing power and redefining roles

In the transitional phase, the physiotherapists began to experience, perhaps for the first time, an unsettling shift of the balance of power away from them and more towards the client. In the medical model framework, the practitioner may believe that their view is dominant. Pattern recognition reasoning does not explicitly take the client's view into consideration when clinical decisions are being made. The physiotherapists were therefore unsure of the extent to which clients and carers should be involved in decision making about treatment plans. In contrast to the hospital environment, staff had little control over the client's life and daily activities. They were now guests in the home of clients and they had to make appointments at times to suit clients. As stated by a focus group member:

You are conscious of the fact that you are in someone's house therefore you've got to abide by their rules. If you are in an out patient department treating a stroke patient, you can impose more of your will. You have to learn to give a little, to gain their trust, before trying to impose your ideas (focus group participant 4).

For a time, some team members tried to preserve 'clinical' authority. For example, the subject of uniform was brought up in a meeting. Some staff expressed the view that they should wear the same type of white tunic as hospital-based colleagues. Those staff in favour of wearing hospital-style uniform felt that it would give them an air of authority and that clients would have more confidence in them. In contrast, I felt it would form a barrier to effective communication between staff and clients/carers and would reinforce medical models of treatment. After discussion, we compromised by agreeing on a smart dress code that would give the team a 'corporate' identity rather than a clinical image.

4.8 THE SETTLING IN PHASE OF DOMICILIARY PHYSIOTHERAPY PRACTICE

4.8.1 Extending the scope of physiotherapy practice

As they 'settled in', the DPS physiotherapists began to extend the scope of their practice. Less emphasis was given to the pursuit of unrealistic goals, such as to restore movement or function

to normal, and more time was spent on working in partnership with the client and carer to identify key problems amenable to therapy. For example, much time in hospital is spent on re-educating the gait of stroke patients, by daily walking practise in the physiotherapy gym. The difficulties the patient may experience, on his return home, in negotiating his own staircase or getting in and out of his own bed may be largely ignored until a pre-discharge home visit at the end of the rehabilitation programme. In their previous hospital context, the physiotherapists may have prioritised goals without any awareness of such crucial home-based problems. To fulfil their role as domiciliary practitioners, the DPS physiotherapists needed to extend their scope of practice, which often involved a shift away from previous models. A focus group member summed up how her practice changed when she came into the community:

You spend less and less of your time doing classic physio - hands on physio, doing treatment regimes - and you end up supporting the carers, acting as a resource for the district nurses ... I'm sure I do the job very differently now from what I thought the job was when I started (focus group participant 1).

The DPS physiotherapists developed skills in prioritisation, which, as discussed in the focus group, are essential in domiciliary practice:

I used to feel overwhelmed. Now I have a much better idea on how to itemise and prioritise problems, and I know who else to contact to help me. My overview is much more solid (focus group participant 2).

An ironic quip made by a very experienced therapist in the focus group illustrates the redefining of professional identity that must take place when an extended community role is taken on:

Going into the community [from out patient work] I had this naive impression that I was going to be working as a physiotherapist out there! (focus group participant 2).

However, an extended role has much to offer, as this quote from the carer of the stroke client confirms:

... physically she doesn't do anything for me, but mentally she does a lot because I have great faith in her (carer of stroke client).

4.8.2 Developing multidisciplinary teamwork

Initially, the physiotherapists tried to reproduce their hospital model of practice and make it 'fit' their new situation. However, once they realised that they could not always solve the client's problems themselves, staff began to open up in discussion, to support each other, share experiences and value the contributions of other professionals. For example, they used their networks of other community-based professionals for advice and guidance, as well as for making referrals. In the focus group, a physiotherapist who worked in learning disabilities recalled her feelings as a new member of community staff:

I thought I had to be responsible, and go in and make decisions, but now I don't do that. You shift it, you share it, you're more sensible about it. We are a resource for the patient - if you can't help them, you know a man who can.

(focus group participant 5).

As discussed in Chapter Four, the original experimental hypothesis that the DPS would reduce use of other services was not supported by the quantitative data on client contacts with other services. There was an unpredicted significant increase in use of other services, which may have followed from the way in which the DPS staff broadened their role as team members. They developed very effective multidisciplinary networks with district nurses and other community based therapists. The carer in the second interview, who saw herself as part of the team, commented on the benefits to her husband of multidisciplinary teamwork:

... they've arranged things between them [the nurse and the physiotherapist] ... they sort of work together and it's turned out right ...between us we'll get there.

(carer of stroke client)

The client with MS in the first interview greatly valued the improvement to his life that had occurred after the domiciliary physiotherapist and the district nurse got together as a team to discuss new ways of moving and handling him.

Concepts of teamwork shift physiotherapy away from a uni-professional to a multidisciplinary perspective. Part of the purpose of my induction programme was to help facilitate the development of multidisciplinary teamwork. As stated in the focus group discussion:

In the hospital, your team is your other physio and OT colleagues, whereas in the community you tend to have to go into a team of other professionals (focus group participant 5).

However, multidisciplinary teamwork in the community can be overwhelming for clients and carers. The same carer of the stroke client who valued the close liaison between the physiotherapist and the district nurse commented on the stress associated with having services provided in her home:

Since he came out of hospital ... I have felt that my home is not my own
(carer of stroke client).

4.9 THE EMERGENT PHASE OF DOMICILIARY PHYSIOTHERAPY PRACTICE

4.9.1 Using negotiation and communication skills

The confident domiciliary physiotherapist had acquired skills and qualities distinct from those of hospital-based practitioners. The following responses came from the focus group when they were asked what makes a good domiciliary therapist. One member highlighted communication skills as the key factor in effective practice:

It's all about communication, and some people are better communicators than others
(focus group participant 6).

Community-based practice requires a high level of interpersonal skill and self-confidence, especially when the practitioner is trying to understand the family system in order to find the

most helpful way of dealing with the problem (Rolland 1994). A focus group member reflected on her own personal development and her ability to 'read' others' behaviours:

It's all about development of your own interpersonal skill, how you interpret a situation, how you read other people's behaviour. It's not about a Bobath course
(focus group participant 5).

The DPS physiotherapists learnt that, in the community, therapy had to be relevant and meaningful for the client. Otherwise, problems were not solved and clients and carers were not satisfied. Negotiation was identified, by one focus group member, as the key to successful intervention:

Maybe you've got to be more realistic. There's no point in going in with your objectives and saying I want you to do this, this and this. You've got to negotiate. They [patients] are much more in control. You can go in with the ideal [piece of equipment] but if the patient isn't happy with that then it will sit in the cupboard.
(focus group participant 2).

The focus group members felt that hospital therapists were just 'catching on' to the idea of agreeing goals with patients, whereas getting the patient's agreement had always been fundamental to good domiciliary practice:

The buzzword at the moment in the hospital is that you've got to agree your treatment with the patient. Well, that's something we've been doing all the time in the community because you know full well things won't get done if you don't. You've got to get their agreement (focus group participant 3).

When reflecting on her husband's treatment, the carer in the second interview made a comment that illustrates the value to the client of effective communication:

It's the way she talks to you, the way she explains things and her attitude
(carer of stroke client).

4.9.2 Seeing the client and carer as active participants in physiotherapy intervention

As they gained more experience, the RCT physiotherapists became less concerned with their 'hands-on' skills and techniques and more focused on the need to work with clients and carers in other ways. They found that physiotherapy knowledge of the causes and likely progression of physical problems could just as effectively underpin educational and counselling approaches as it could movement facilitation or exercise techniques. They worked extensively with carers, and were enlightened by spending time in the 'real life' situation. A focus group member recalled witnessing, first-hand, a carer putting herself at risk.

Before, [in hospital practice] you see the patient as the patient and the carer is incidental. Whereas when you go into the home you actually see them struggling on with a certain task. And, just by being there, you can say, "well I can show you an easier way of doing that" (focus group participant 2).

Carers benefited from contacts with physiotherapists in ways that are very difficult to measure. The carer in the second interview described how the physiotherapist had included her in her husband's treatment right from the beginning:

We had a talk, and she said, "He's got a long way to go, but between us, we'll get there" (carer of stroke client).

The same carer welcomed the way the physiotherapist viewed her as part of the team. Through contact with the DPS physiotherapists, she had acquired new skills and confidence and the reassurance that back up was available if required. Throughout the trial, the team acquired large caseloads, as the decision to discharge a client was often difficult to make. In hospital practice, the decision to send a patient home is ultimately made by the medical staff, and therapists' caseloads may be defined by the number of beds on a ward. In the trial, if carers felt empowered with new coping strategies, withdrawing from a case was much easier, as a carer explained:

I know what I'm doing. If we hit problems, I have her number and I give her a ring... As time goes on she'll not come so often. Then I will take some of her work over, as she's explained it to me (carer of a stroke client).

As staff moved through the emergent phase, models of practice developed in which clients and carers were active participants from the first visit. As stated by a focus group member:

Ideally they [clients] have got to be happy, ultimately, with what you're doing and what you're suggesting so you have to have their fundamental agreement otherwise you'll get nowhere (focus group participant 1).

4.9.3 Redefining goals for physiotherapy intervention

The team became concerned with goals that were meaningful to clients/carers. Priorities were re-aligned, as illustrated by this quote from the focus group:

When you go in to see a man who had his stroke two days ago and physically can't get to the loo, the first job you have to do is teach his wife, never mind doing physio on the patient. You've got to first teach the wife how to do a transfer from bed to commode. No, actually that's the second thing, the first thing is to try to urgently find a commode (focus group participant 1).

At the start of the trial, the physiotherapists would have viewed delivering a commode as menial work. Once involved with clients and carers, the human side of intervention became just as important. Providing a piece of equipment that is going to make a real difference to someone's quality of life was seen as valuable. As explained by an Occupational Therapist in the focus group:

I think we take responsibility because it's expedient and because we get some benefit ourselves from the interaction - that we are of some use, no matter at what level. (focus group participant 3).

Doing things such as providing equipment is an investment in the relationship with the client and carer:

It's on a human level - if your practice is based in a good relationship with the family, then it [fetching a commode] is conducive to developing that relationship, it's a long term investment (focus group participant 3).

Finally there was a full realisation that goals are only relevant if they are meaningful to the client, as illustrated by the following focus group quote:

... you treat the patient as a whole and what is a problem to the patient you may not automatically assume would be a problem. You've got to get from the patient what they see as their problems and try to eradicate these problems (focus group participant 6).

4.9.4 Using intuition and experience to create new knowledge

In the emergent phase, the RCT domiciliary physiotherapists seemed to become intuitive practitioners who could subconsciously recognise social, cultural and behavioural cues, which helped them to develop treatment strategies. Intuitive practice can be problematic if therapists bring their own value judgements to bear on the client's situation (Paley 1996). However, communicating intuitive feelings to the client may facilitate shared decision-making and thus enhance the effectiveness of practice. The following quote from the focus group sums up the dilemmas faced by domiciliary physiotherapists, as there is little research evidence on which to base their practice:

A lot of what underpins what makes a difference to what you actually do isn't the research paper you read. It's your intuition which is based on a whole host of things from your past experience, both professionally and otherwise (focus group participant 1).

Experience, rather than knowledge per-se, was seen by the focus group as pivotal in 'expert' domiciliary practice:

You do eventually reach a level where experience influences your work more than anything else (focus group participant 2).

Confidence in practice correlated strongly with experience. As time passed, the domiciliary physiotherapists began to feel at ease with their role. As stated in the focus group:

It's only once you've seen ten or twenty patients with the same problem it starts to make sense (focus group participant 2).

5. SUMMARY

In this chapter the process of domiciliary physiotherapy has been analysed quantitatively and qualitatively. Data on clients' diagnosis and the GPs' reason for referral could be used to inform future service specifications. Referral and diagnostic information could also be used to educate physiotherapists and GPs embarking on new service arrangements. The quantitative analysis of number of visits and episodes of intervention has provided useful data for predicting levels of future service provision. For example, new services need to have the capacity to make an average of 12 visits over a 12 week period for each client, but should also be able to cope with the needs of small numbers of clients who may require many visits over long periods of time. The interpretive analysis of practice has added another dimension to knowledge of domiciliary physiotherapy. The theoretical phases of domiciliary physiotherapy practice development may provide insight into how 'new' practitioners could be supported and guided in their work.

In the next chapter, results presented in this and previous chapters will be critically discussed, and the interpretive account of domiciliary physiotherapy presented in this chapter will be further developed to suggest a model of domiciliary physiotherapy practice.

CHAPTER SIX

DISCUSSION

1. OVERVIEW OF CHAPTER

The final chapter of this thesis will, firstly, discuss the main findings of the trial of domiciliary physiotherapy in terms of internal and external validity, and the relationship between these findings and those from other research. There will then be a critical review of the randomised controlled trial in the context of evidence-based practice. The process of domiciliary physiotherapy will be discussed in terms of theoretical concepts of 'knowledge and expertise', 'models of practice' and 'power and control'. A new model of domiciliary physiotherapy practice will be proposed and, finally, recommendations will be made for the way forward in domiciliary physiotherapy practice and research.

2. DISCUSSION OF THE MAIN FINDINGS OF THE TRIAL OF DOMICILIARY PHYSIOTHERAPY

This section will review the effect of domiciliary physiotherapy on clients' activities of daily living and health status, and the impact of the DPS on clients' use of other services. Substantive non-significant and significant findings, previously presented in Chapter Four, will be juxtaposed with qualitative data on client and carer perspectives. Alternative explanations for these findings will be suggested and their relationship with previous research will be considered.

2.1 THE EFFECT OF DOMICILIARY PHYSIOTHERAPY ON CLIENTS' ACTIVITIES OF DAILY LIVING AND HEALTH STATUS

There were no statistically significant differences between the experimental and control groups in change in Barthel Index or Nottingham Health Profile scores, at either 3 or 12 months. Therefore, there was no evidence that domiciliary physiotherapy made any measurable difference to clients' level of independence in activities of daily living or health status, as

measured by the Barthel Index and the Nottingham Health Profile. However, the clients and carer interviews provide insight into the potential value of domiciliary physiotherapy in terms of providing hands on physiotherapy intervention, teaching the client and carer new skills, giving advice, providing emotional support and liaising with other services. Experienced community-based therapists stated in the focus group that they believed that community-based intervention made a difference, through individualised treatment, carer support and a therapeutic relationship which placed importance on client/carer perspectives of the problem.

The results of the DPS trial do not provide conclusive evidence about the effectiveness of domiciliary physiotherapy, and other published trials involving domiciliary physiotherapy tell a similar story. Trials that have compared domiciliary physiotherapy (as a 'single' therapy) with other forms of rehabilitation have been conducted in the field of stroke rehabilitation. Young and Forster (1992) showed that home-based physiotherapy was only slightly more effective than day hospital attendance, for stroke patients recently discharged from hospital; and Wade *et al.* (1992) found that domiciliary physiotherapy intervention resulted in a small short-term improvement in mobility, for patients living at home more than a year after their stroke. Other trials of home-based rehabilitation have assessed physiotherapy as part of a multidisciplinary package. The results are useful, but not directly comparable with those of domiciliary physiotherapy trials. In the field of stroke care, Gladman *et al.* (1993) concluded that there was no difference in the effectiveness of domiciliary and hospital-based rehabilitation services, although younger patients discharged into the community from stroke units (rather than other in-patient environments) appeared to do better with home therapy. Similarly, Rudd *et al.* (1997) found no differences between specialist multidisciplinary domiciliary rehabilitation and conventional care for stroke patients discharged early from hospital. In a very recent trial (Baskett *et al.* 1999) the trend of inconclusive findings continues, with no difference detected on a range of measures, including walking speed and ADL, between patients doing self directed home-based exercises under weekly supervision by a physiotherapist or occupational therapist,

and patients receiving conventional outpatient or day hospital therapy after stroke. In a trial of home exercise programmes, elderly patients with limited mobility were randomised to receive either strength exercises, mobility exercises or health education (McMurdo and Johnstone 1995). All subjects were visited at home by a physiotherapist for 30 minutes every 3-4 weeks, and the results showed no differences in assessments of 'sit to stand' ability and timed 'get-up-and-go' mobility tests.

A recent Audit Commission project was set up to *understand the present state of knowledge of the clinical effectiveness of rehabilitation using the evidence of systematic reviews* (Sinclair and Dickinson 1998). The resulting report reviewed systematic reviews across a range of different clinical areas defined by client group, disability or disease, and identified two types of rehabilitation: packages of care and simple interventions. In both types of rehabilitation, detail about the components of intervention was lacking and the authors concluded that the boundaries of rehabilitation were *fuzzy* (Sinclair and Dickinson 1998). Outcome measures were seen to require further development in order to facilitate comparison across different studies and pooling of results. The evidence from the systematic reviews came out against simple or single interventions, which may underline the finding that the DPS was not effective. The report suggested that individually weak interventions may be more effective when they are offered together in a co-ordinated package, and service organisation of multidisciplinary teams may provide a good environment for goal setting, training and specialisation, which may be prerequisites for successful rehabilitation (Sinclair and Dickinson 1998). Of a total of 56 systematic reviews 14 were categorised under mixed, community or primary settings. However, the focus of these reviews was mostly irrelevant to domiciliary physiotherapy, e.g. diabetes care, psychiatric consultation, bibliotherapy. One meta-analysis of trials of geriatric assessment (Stuck *et al.* 1993) was picked out in the report as providing evidence of the importance of different phases of the rehabilitation process and of the role of assessment in determining the setting and nature of rehabilitation. The transferability of interventions from hospital to

community settings was highlighted as a limitation of current evidence in rehabilitation, and it was recommended that future research should more fully consider the role and effectiveness of rehabilitation outside hospital environments.

In the case of the present trial of domiciliary physiotherapy for a 'mixed' disease/disability population, the absence, in a single study, of statistically significant findings does not justify acceptance of the null hypothesis. Problems related to external, internal and statistical conclusion validity may lead to a failure to detect real differences. Other methods of statistical analysis may reveal undetected findings. For example, Matthews et al (1990) suggest that calculating the area under the curve of plotted data, instead of applying inferential statistical tests to computed differences in scores, may provide a useful way of analysing outcomes of intervention. There may also be scope for exploring the effects of domiciliary physiotherapy further using regression techniques. Before deciding whether or not to accept that domiciliary physiotherapy made no difference, threats to internal and external validity need to be systematically examined. Cook and Campbell (1979) define internal validity as the extent to which the relationship between the independent and dependent variables is causal, and external validity as the extent to which any presumed causal relationships can be generalised to and across different types of persons, settings and times. The following sub-sections will review the impact of statistical power, sensitivity of measures, differential sample attrition, the nature of domiciliary physiotherapy intervention and sample representativeness on internal and/or external validity. Finally, summary conclusions on the effect of domiciliary physiotherapy on clients' independence in activities of daily living and health status will be made.

2.1.1 Statistical power and internal validity

Group experimental designs rely on changes in outcome being sufficiently large to be detected statistically (Altman 1991). In the DPS trial, clients recruited had long-term chronic conditions, where measurable improvements were likely to be small. In a trial of home-based physiotherapy

for long-term stroke patients, Wade *et al.* (1992) were able to show only a small average increase in walking speed, which was not maintained after treatment ended. To allow for the detection of small changes, a large sample size was required for the DPS trial (800 subjects) to give an 80% chance of detecting a difference of 10% between the two groups. However, as noted in Chapter Two, the sample of 245 recruited fell far short of the number required. Thus the statistical power of the experiment was substantially reduced, increasing the likelihood of making an incorrect no-difference conclusion, i.e. a type II error (Cook and Campbell 1979). For example, non-significant improvements in the areas of mobility, as measured by the NHP, and performance on stairs, as measured by the Barthel, have been identified. These findings may be important indicators of the effectiveness of domiciliary physiotherapy but, as they do not quite reach statistical significance, they can not be used as definitive evidence on which to reject the null hypothesis. With a larger sample, significant differences between the two groups might have been detected. The possible explanations for poor recruitment were varied and have been debated in a published paper (Dawson and Heyman 1997. See Appendix 13). Some GPs claimed that the withholding of domiciliary physiotherapy from the control group would deprive clients of clinical benefit. However this claim was not justified as there had never been a domiciliary physiotherapy service in Newcastle, and claims about the value of such a service were based on speculation. Other GPs objected to the RCT on the grounds that, as doctors, they should be able to freely access any service they felt would benefit their patients. It is possible that GPs felt unwilling to admit to patients that they were unsure of the best treatment (Taylor *et al.* 1984).

The problems discussed above are not unique to this trial of domiciliary physiotherapy.

Tognoni *et al.* (1991) described the difficulties experienced by a group of Italian researchers attempting to conduct an RCT of the treatment of hypertension in general practice. They found a large discrepancy between the number of doctors who agreed to participate and the number who started recruiting, leading them to question the attitude of Italian GPs towards controlled

research. Following the publication of the Tognoni paper, two letters were published in the British Medical Journal (BMJ) telling of similar experiences. Peto and Coulter (1991) wrote to the BMJ editor about their study of outcomes of treatment for menorrhagia in Oxford, in which they had to extend their recruitment phase because of lower than anticipated recruitment of patients by GPs. Two months later, Jonker and Sumajow (1992) wrote about their surveillance study of reflux oesophagitis in The Netherlands, in which, after a year, many GPs who had promised to co-operate had referred no patients. Greenberg (1991) congratulated Tognoni *et al.* for raising awareness of a problem that is usually glossed over in reports of trials in general practice. Some GPs in the DPS trial were blatantly honest at the outset, saying that they supported the trial in principle, but were unlikely to recruit subjects due to the extra work involved in obtaining consent and collecting data. Extra workload has been cited as a predictable disincentive to GP involvement in trials (MacIntyre 1991). A financial incentive such as that given in many drug trials can compensate for extra workload (Waldron and Cookson 1993), but there is no evidence that paying GPs would have improved recruitment to the DPS trial.

The experience of the DPS trial indicated that GPs learned about how to select and refer appropriate patients as they went along. Perhaps a future trial in Newcastle would be less problematic, given that GPs are now more experienced. However, it would be difficult to gain ethical approval, as the DPS was continued as a mainstream service after the trial ended.

Taylor (1992) discusses reasons for GPs' reluctance to enter patients into trials. She surveyed general physicians involved in a multi-centred clinical trial in the USA and Canada, and found that poor recruitment of patients was linked more to the social process of the RCT than to any inherent resistance or reluctance to support research. Although general physicians publicly argued that experiments were ethically wrong, or trials were too time consuming, Taylor found that they were privately struggling with conflicting professional roles. American and Canadian

general physicians (and presumably British GPs) normally get their rewards and social status from their individual doctor-patient relationship. They are supposed to reduce uncertainty for the patient, apply their knowledge, skills and experience to individual patient problems, and then receive personal appreciation from patients and families when there is a successful outcome. Physicians surveyed in this RCT of treatment of eye cancer felt uncomfortable about random allocation taking over their decision making role, and they disliked admitting to patients that they didn't know which was the best treatment for them. They were uncertain about whether they could remain motivated to carry out administrative tasks when research was not perceived as high status work in general practice. Many physicians were also worried about shifting their allegiance from the present patient to future patients who would stand to benefit from the results of the RCT. The GPs involved in the trial of domiciliary physiotherapy must also have faced the dilemma of conflicting professional roles. However, because patients in the trial would be likely to benefit from the future service if the RCT were successful, the issue of asking patients to participate in a trial that would not benefit them directly did not really arise.

2.1.2 Sensitivity of measures and internal/external validity

The Barthel Index and the Nottingham Health Profile were chosen for their claimed ability to differentiate between the abilities/health status of multi-diagnostic groups, and for their widespread use, at the time, as rehabilitation outcome measures. The Barthel Index is widely regarded as a reliable and valid measure, particularly in the field of stroke rehabilitation (Gompertz *et al.* 1994, Shah 1994). According to Shah (1994) the Barthel can be used with outpatients, in-patients, day-care patients and those from various age and disability groups. It has been claimed it can be administered reliably by postal, telephone and face-to face methods (Yeo *et al.* 1995). However, as an outcome measure of *physiotherapy*, rather than multidisciplinary rehabilitation, the Barthel Index has been criticised for its lack of sensitivity (Ashburn *et al.* 1993, Simpson and Forster 1993, Smith 1993). In a previously mentioned trial of physiotherapy for long-term stroke patients it failed to detect differences in patients who had

a significant improvement in walking speed (Wade *et al.* 1992). The ceiling effect of the scale created problems in the DPS trial. At baseline the sample median BI score was high up the scale, limiting the extent to which the scale could measure improvement in the better cases remaining in the trial at 12 months.

Similarly, the Nottingham Health Profile did not detect change in the DPS trial. In other trials of physiotherapy (Gladman *et al.* 1993, Young and Forster 1992), the NHP was also insensitive to change. The failure to reject the null hypothesis in the DPS trial may thus have been due to the inability of the Barthel Index and the NHP to measure change. Real changes in functional ability and health status may have resulted from domiciliary physiotherapy intervention but not been detected. Thus it may not be safe to generalise from the lack of a difference on these measures, thereby reducing the external validity of the study. Alternative scales of measurement, available since the trial, may show a significant outcome in future trials. For example, the Canadian Occupational Performance Measure (COPM) (Law *et al.* 1990) assesses individual outcome in client-identified areas relating to self-care, productivity and leisure. After selecting and ranking up to five specific functions that they find problematic or difficult, clients then rate, on scales of 1-10, their performance in these functions and their satisfaction with that performance. Total scores can then be calculated before and after intervention. Although the COPM was designed for use in occupational therapy, it may have relevance for any intervention where the goal is not only to restore or develop physical function, but also to help clients to cope with residual functional impairment. By scoring satisfaction as well as performance, the COPM can identify cases where self-rated functional performance has not measurably changed, but the client has become more satisfied with that performance. Carer outcomes from domiciliary physiotherapy intervention could be assessed using a specific measure such as the Carer Strain Index (CSI) (Robinson 1993), which elicits a series of yes/no responses from carers, in order to identify the burden imposed by caring. Several areas are covered in the CSI, including physical strain, sleep disturbance, emotional adjustment and

feeling overwhelmed. The areas of physical strain and feeling overwhelmed may be particularly useful indicators of DPS intervention, given that the carers interviewed indicated they had learned easier ways of moving and handling the person they were caring for, and felt more positive about managing problems in the future.

2.1.3 Differential sample attrition and internal/external validity

Overall sample attrition was higher in the control group (38%) compared with the experimental group (29%), but the difference was not significant (chi-square=2.34, $p=0.13$). However, because differential sample attrition presents a serious threat to internal validity (Cook and Campbell 1979) any differences between the rates of attrition in the two groups must be investigated. Although clients who *refused* to be interviewed (rather than dropped out for other reasons) formed only a small proportion of total dropouts, the difference between the two groups in refusal rates was highly significant. In the experimental group there were 2 refusals (2% of total clients recruited) compared to 13 refusals (11% of total clients recruited) in the control group (chi-square=8.95, $p=0.003$). When research fieldworkers visited clients who had been recruited to the trial, it became apparent that, despite agreed protocols, individual GPs had given many different explanations of the trial. Some control group clients had been led to believe that they would receive domiciliary physiotherapy, and they were dissatisfied when they found out they would not. Although GPs might have been deliberately sabotaging the trial by raising false expectations, it is more likely that, because of their lack of research training, they were unaware of the implications of deviations from the research protocol (Jonker and Sumajow 1992). Resentment and refusal to co-operate can be easily provoked when subjects perceive that treatments vary in desirability (Cook and Campbell 1979). Using research fieldworkers to obtain consent may have prevented the problems caused by GPs failing to follow the agreed protocol, and may have reduced the numbers who subsequently dropped out of the trial.

Sample attrition led to systematic bias where those worse off, in terms of independence in activities of daily living and social isolation, were lost to the trial (see Chapter Three). In consequence, those present at the final measure were substantially different from those recruited to the trial, casting doubt on external validity, i.e. the extent to which the findings can be generalised to and across different types of persons, settings and times (Cook and Campbell 1979). If the worst cases had not dropped out a measurable difference may have been detected, as those with lower initial Barthel and NHP scores had the most potential for measurable improvement (see Chapter Four). As it stands, the null finding should not be generalised to other DPS services as it may relate to a more able, less isolated, sample of clients than those likely to be referred. The null finding could be just as easily due to a selection artefact, i.e. the factors specific to the trial caused loss from both groups of those who might have benefited.

2.1.4 Domiciliary physiotherapy intervention and internal/external validity

Domiciliary physiotherapy is a multi-faceted therapy, involving physical treatment, health education and counselling. A pragmatic trial was conducted, so that the exact nature of intervention could differ in each case as necessary (Schwartz *et al.* 1980). The relationship between the independent and dependent variables thus becomes less tangible, as non-standard intervention complicates the causal logic of the RCT by introducing multiple treatment variables that interact. As previously discussed in Chapter Five, the DPS staff developed their role as the trial progressed. They needed time to settle into community-based practice and it should be acknowledged that their early intervention might not have been well targeted towards outcomes that measured disability/handicap. Trialing a new service before implementing it creates a dress rehearsal scenario (Bond *et al.* 1989b) where, on the one hand, atypically high human and monetary resources may lead to better than usual service provision, or, as in this case, new innovative services are evaluated before they have fully matured. Although there was a pre-trial period, the domiciliary physiotherapists continued to develop their practice as the trial progressed. Different physiotherapy, given by different physiotherapists, may have

produced more measurable effects; or simply allowing the service more time to develop before testing it may have created a better context for successful, generalisable evaluation.

2.1.5 Sample representativeness and external validity

Sample representativeness should be considered as one factor contributing to external validity. As far as could be assessed, the initial sample recruited was representative of clients referred to other domiciliary physiotherapy services (see Chapter Three). However, the extent to which the sample was representative of all people requiring domiciliary physiotherapy is, theoretically, open to some question. Since the DPS was reliant on GPs to identify suitable clients, there may have been people who could potentially benefit from domiciliary physiotherapy who were not identified or referred. A comparison of the sample referred to the trial with the first 85 clients referred after randomisation ended revealed that the post-trial sample had a greater proportion of clients with communication problems. The trial sample was, therefore, not fully representative of clients referred to the on-going service. As mentioned in the previous paragraph, using a trial as a dress rehearsal for a new service often leads to problems with generalisation. Consideration of the difficulty of obtaining informed consent from someone with a communication problem may have inhibited GPs from recruiting such patients to a trial, but would not deter them from referring someone to a mainstream service.

2.1.6 Conclusion

The failure to reject the null hypothesis may have been due to the smaller than intended overall sample size, the masking of real effects by differential sample attrition, the loss of clients most likely to improve from both the experimental and control groups, or lack of sensitivity of the outcome measures. However, since the evidence of systematic reviews favours multidisciplinary rehabilitation over single therapy it must also be considered that domiciliary physiotherapy was simply not effective. Comments from clients, carers and therapists suggest that domiciliary physiotherapy may be beneficial, but as these comments derive from only two client/carers interviews and one focus group of therapists, they should be regarded as no more

than tentative findings, which would need to be verified through further sampling and analysis of concepts. Based on the evidence from this study, it can not be concluded that domiciliary physiotherapy intervention was ineffective, only that the domiciliary physiotherapy service tested had no detectable effect.

2.2 THE IMPACT OF THE DPS ON CLIENTS' USE OF OTHER SERVICES

2.2.1 Overview

The experimental hypotheses predicted that the DPS would reduce clients' use of other health and social services, and would also lessen the number of referrals by GPs, admissions to hospital and episodes of respite care. In general, this study has shown that very few clients had any contact at all with social services. The number of referrals by GPs was significantly reduced, by a very small median difference of less than one referral in the domiciliary physiotherapy group. Although there was no significant difference in hospital admission rates, access to the DPS did significantly reduce length of stay in respite care. Exploratory analysis suggested that clients who attended day hospital made fewer visits if they were receiving domiciliary physiotherapy. However, overall, access to the DPS significantly increased, rather than decreased, the proportion of clients having at least one contact with another health or social service. This section will discuss, firstly, the main finding that domiciliary physiotherapy increased the likelihood of clients having at least one contact with another health/social service. Subsequently, associated findings, i.e. that few clients had any contacts with social services, and that the DPS reduced clients' use of day hospitals, respite care and the number of GP referrals, will be discussed.

2.2.2 Domiciliary physiotherapy increased the likelihood of clients having at least one contact with another health/social service

For the total sample, i.e. sample 2, who returned diary data, and for whom GP record card data were available (n=222) domiciliary physiotherapy significantly increased the likelihood of

clients having at least one contact with another health or social service. Sample 2 includes data provided from clients who refused to be interviewed but who agreed to provide diary data. The inclusion of data from these clients allows some of the worst cases to be represented in the analysis, e.g. several control group clients who were receiving no services. These cases are not atypical. In a community-based study of services for the elderly (Allen *et al.* 1992) it was found that most people had only one or two services, and that some had none at all. Instead of reducing other contacts, as hypothesised, the DPS enabled clients to access other services. Discovering a statistically significant result in the opposite direction to the specified hypothesis increases the level of confidence with which it can be concluded that the predicted effect was not obtained under the conditions of the study (Cook and Campbell 1979). In other words, domiciliary physiotherapy did not reduce clients use of other health or social services. On the contrary, domiciliary physiotherapists actively referred experimental group clients on to other members of the primary health care team. However, as this finding is based on patient reported contacts with other services, it should be treated with caution. Luther et al (1998) found that there was variability in the degree of agreement between stroke patients and service providers on the contacts patients had received. Whilst there was good agreement between patients' reports and service records on contacts with social services occupational therapists, there was poor agreement for contacts with hospital occupational therapists. Agreement between patients' reports and hospital records on admissions to hospital and outpatient appointments was fair, but there was poor agreement for hospital physiotherapy contacts. Possible reasons why the DPS might have taken on the role of gatekeeper to other services will now be considered.

In the early transitional phase of the DPS, staff were confronted with many unfamiliar problems. They were more exposed to the cultural, social and psychological components of disease/disability than they would otherwise have been in a hospital situation. Community-based practice presents complex challenges to professionals used to working in institutional environments. They have to balance their own view of 'what is best' against client choice, in

the context of limited resources, often with clients for whom long-term management may be the only therapeutic option, and within a culture that is more familiar to the client than to them (Heyman 1995b). The DPS staff were introduced to a network of other community-based professionals during the induction period, to help orientate them to their new 'work environment'. This induction heightened their awareness of the opportunities for referral and may have encouraged them to 'refer-on' as a way of coping with unfamiliar problems. By transferring or sharing responsibility for client problems, staff may have relieved pressure on themselves. On the other hand, as the DPS 'settled in', the staff broadened their role perspective and may have begun to have a more contextualised view of clients needs. Real unmet need, requiring a referral elsewhere, may well have been identified. Experienced therapists in the focus group discussed the transition they made, from feeling totally responsible for all problems, to recognising the contribution that other professionals could make to the client's care. Community-based practice requires teamwork, and primary health care professionals should not work in isolation of each other (Jarman and Cumberlege 1987). The potential for the physiotherapist to identify the need for other rehabilitation services has been cited as a possible advantage, to the GP and the client, of the development of domiciliary physiotherapy services (Burnard 1988). Liaison with other services was perceived, by clients and carers, as a benefit of the DPS. One of the clients who was interviewed particularly valued the way the physiotherapist had put herself out, even at night-time, to meet with all the nurses involved in his care so that she could teach them more effective and comfortable ways of moving and handling him.

However, bringing multiple professionals into someone's home does have drawbacks. Although professionals may feel they are offering a comprehensive multidisciplinary service, clients and carers can feel as if they have been intruded on. One of the carers who was interviewed felt that her home was no longer her own when her husband began to receive several daily visits from the district nursing service on his discharge from hospital. In terms of the cost effectiveness of

the DPS, introducing a service, which then refers on to others, is expensive. However, an increase in services, in the short term, may lead to savings, in the long term, if future dependency is reduced or hospital admissions are averted. For example, if a client is unable to walk due to painful foot deformities, a referral by the domiciliary physiotherapist to the chiropodist can result in a dramatic return to independent mobility once corns, calluses or long toe nails have been treated and appropriate specialist footwear prescribed. Moreover, access to services could result in potential benefits for carers as well as clients if their needs are more fully considered.

2.2.3 Few clients had contacts with social services

Nearly all clients (98%) had contacts with health services, compared with only 28% who had contacts with social services. The main social services professionals seen by clients were occupational therapists and social workers. Given that the clients referred to the trial were, by definition, in need of physiotherapy, it is likely that many of them also required enabling equipment, such as wheelchairs, bath aids, stair rails, etc. At the time of the trial, the waiting list for social services occupational therapy assessment, required before certain pieces of equipment could be provided, was several months long. Recent papers suggest that problems in access to social services occupational therapy still exist. In a survey of older people and their carers, following discharge from hospital, Shepherd (1996) found problems arising from lack of provision of key items of equipment and home adaptations. Logan *et al.* (1997) found a mean waiting time of 22.5 days between referral and the first visit by a social services occupational therapist, and that, on average, only 2.5 visits were made.

Influential policy papers on community care (Griffiths 1988, Department of Health 1989) were being circulated and discussed at the time the DPS trial was being planned and implemented. These papers made recommendations, later incorporated into the NHS and Community Care Act (Department of Health 1990), that social services should be given responsibility for the

care management of elderly and disabled clients in the community. The results of the DPS trial indicate that, in Newcastle, social services were not playing a major role in the care of such clients. The wisdom of giving care management responsibility entirely to social services was questioned by Dowrick (1992), who expressed concern about the transfer of decision making from GPs. While there is no evidence to suggest that GPs were already fulfilling a care manager role, or that they could do a better job than social services, Dowrick's concerns illustrate the continuing interagency disputes over who can give the best care (Dalley 1996).

As the proportion of older people in the population rises, more frail and vulnerable people will require care. From a service user perspective, artificial divisions between health and social care do little to promote needs-led continuous service provision (Wistow 1994). It is becoming increasingly difficult to justify the separation of health from social care whenever secondary prevention can not alleviate a problem, and the implementation of the NHS and Community Care Act has done little to improve relations between health and social services (Tinker 1996). Henwood (1995) predicted that there would be growing uncertainty regarding the roles of health and social care, as increasing numbers of dependent people are cared for in the community. Following a decade of contracting-out of services to the independent sector, health and social services have less and less direct control over service provision for the elderly. Despite the rhetoric of policy, it seems there is still a long way to go before the interface between health and social care becomes seamless. Domiciliary physiotherapists can help to bridge the gap between services by assessing the health needs of clients in their home environment. For example, rehabilitation programmes prescribed in a hospital setting may fail to recognise barriers or opportunities created by the client's environmental and social circumstances. A social services assessment of a disabled person at home may pay attention to the environmental and social factors but, by not taking into account the 'physical potential' of the individual, may fail to identify the possibility of rehabilitation. By offering a health service such as physiotherapy in the home setting, realistic rehabilitation programmes can be

implemented in the light of available carer support and within the limitations of the client's home surroundings.

2.2.4 Domiciliary physiotherapy may reduce clients' use of day hospital services

Among the small sample of 9 who attended day hospitals, clients who received domiciliary physiotherapy made fewer visits than clients in the control group (exact 2-tailed $p=0.04$), suggesting that access to the DPS may reduce the need for day hospital attendance. Day hospitals provide intensive rehabilitation for elderly people, either as a part of the transition from in-patient care, or to prevent admission to hospital for community dwellers. However, little evidence exists to support the effectiveness of day hospital rehabilitation. Young and Forster (1992) found that domiciliary physiotherapy was more effective than day hospital rehabilitation for stroke patients. The above finding of the present study may suggest that the domiciliary physiotherapy in the DPS trial was, for some, an effective substitute for day hospital rehabilitation. Participants in the focus group discussed the ways in which rehabilitation in the community can be tailored to the immediate needs of the client, and a carer noted the physiotherapist's adjustment of her approach to meet the specific needs of her husband. The therapist withheld conventional physical activity until she had first gained his trust and improved his confidence. Day hospital care has been shown to be more costly than community-based rehabilitation (Tucker *et al.* 1984). More than two day hospital attendances per week can be as expensive as in-patient care (Hildick-Smith 1985). At the time of the trial, a visit to a day hospital in Newcastle cost £21 per hour, compared to £18-50 per hour for domiciliary physiotherapy. As clients are likely to stay for several hours at each day hospital attendance (Forster and Young 1989), and the average number of attendances has been estimated at 20 per patient (Hildick-Smith 1985), there are potential cost savings to the NHS if domiciliary physiotherapy is provided instead of day hospital rehabilitation.

2.2.5 Domiciliary physiotherapy may reduce clients' use of respite care

For the small sample of 12 who used respite services, the control group had a significantly longer median length of stay (exact 2-tailed $p = 0.01$). Of all services for care of the elderly, respite care stands out as the one designed for carer, rather than client, support. One of the most frequent requests made by carers is for a break from the demands of caring (Nolan and Grant 1990). The reasons why domiciliary physiotherapy may have reduced clients' use of respite care are considered below.

Jones and Vetter (1986) suggest that those most in need of respite care services can experience most difficulty in obtaining them. The results of the DPS trial show that only 14% of those who had carers received any respite care. There were indications from the qualitative data that domiciliary physiotherapy can provide both emotional and practical support to carers. In both hospital and community environments, physiotherapists have a key role in teaching and monitoring safe and effective moving/handling techniques. In the DPS trial, all carers were offered advice and education on the best/most efficient way to move and handle their relative. A carer who was interviewed told how much their lives had changed for the better since the physiotherapist taught her and the district nurses a new way of transferring her husband. However, such a change would not be picked up by either the Barthel Index or the Nottingham Health Profile. A participant in the focus group emphasised the key role community-based professionals play in recognising carer needs.

Although they get a complete break from the physical strain of caring when their relative is in institutional care, carers can often feel burdened by guilt about 'sending their relative away' and they are not always satisfied with the quality of institutional respite care provided (Martinus and Severs 1988). Also, most elderly people, even if severely dependent on others, would prefer to be managed at home (Salvage *et al.* 1988). Practical advice and help for carers, such as that provided by the DPS, may be an alternative option to full-time respite care outside

the home. The assumption that older people would prefer to be cared for by a relative has been challenged by Daatland (1990) who found that some older people would prefer to have services provided by professionals rather than their families. Older people have expressed the view that their least preferred option for care would be to live in their married child's home (Arber and Ginn 1991). Government policy clearly favours care from relatives and friends over the more expensive option of formal services (Audit Commission 1985). A recent consultation paper (Chancellor of the Exchequer *et al.* 1996) stated that long term care in a person's own home would remain the pivot of care in later life. Provision of support to carers enhances the likelihood of older people remaining at home (Walker 1982) and the needs of carers were emphasised in the White Paper 'Caring for People' (Department of Health 1989). The DPS trial has found that domiciliary physiotherapy may reduce the need for institutional respite care by offering practical advice and emotional support for carers. Although tentative, this finding warrants that future evaluations of domiciliary physiotherapy services should take into account carer outcomes when choosing measures of success.

2.2.6 Domiciliary Physiotherapy may reduce the number of GP referrals to other agencies

Nearly half of all clients in the DPS trial had no referrals made for them by the GP, other than the referral to domiciliary physiotherapy. However, in the sub-group of clients who did have referrals (n=89), the control group were more likely to have at least one (p=0.02) other than the referral to the DPS. In terms of cost effectiveness, introducing domiciliary physiotherapy could result in cost savings by reducing the need for GPs to refer to other agencies. However, since physiotherapists are more likely to refer clients on to other agencies, the cost saving on GP referrals disappears. No other community-based rehabilitation trials have assessed the effect of therapy services on GP referrals to other professionals, probably because previous trials have been led by hospital physicians and have focused on hospital in-patients discharged into the community, rather than on community-dwelling individuals. The working relationship between the GP and the domiciliary physiotherapist is relatively new, compared to that between

consultants and hospital based physiotherapists. As has been suggested by Burnard (1988), the GP could benefit from using a domiciliary physiotherapist to assess patients' needs for other rehabilitation services.

2.3 CRITICAL REVIEW OF RANDOMISED CONTROLLED TRIALS IN THE CONTEXT OF EVIDENCE BASED PRACTICE

The National Health Service Executive published an instructive paper on clinical effectiveness (NHSE 1996) which set out the requirement for health care interventions to be evidence-based, and introduced the concept of hierarchies of evidence. Randomised controlled trials held the position at the top of the hierarchy, followed by robust experimental or observational studies, and expert opinion was seen to be the 'lowest' form of acceptable evidence. More recently, strong evidence from at least one systematic review of multiple well-designed RCTs has dethroned the single RCT as the highest form of evidence (Sinclair and Dickinson 1998). Although the DPS trial pre-dated current drives for evidence-based practice, the RCT design was chosen because of its ability to provide 'gold standard' evidence. However, the experience of conducting the evaluation of domiciliary physiotherapy has raised issues about the RCT, which are rarely discussed in reports of trials.

The RCT may have limited the validity of the findings, by narrowing the focus of outcome measurement before an in-depth understanding of the phenomenon was gained. The study of the process of domiciliary physiotherapy, discussed in the next section, provided insight into carer benefits that were not measured in the primary outcomes of the trial. Choosing the RCT design determined not only a research method, but also a way of framing the research problem. The incidental data on the process of domiciliary physiotherapy has provided insights which go beyond answers to the simple question 'is domiciliary physiotherapy more effective than conventional care?'. Observational studies come near the bottom of the hierarchies of evidence, yet the insight gained from observation may be an important stage in researching a phenomenon

(Black 1996). We need to be wary of rejecting the value of interventions on the basis of non-significant results from single experiments. If research is to be relevant to community-based practice, we need a broad approach to methodology, which utilises the best features of experimental and non-experimental techniques, in order to answer the range of research questions that must be asked (Dawson and Heyman 1997. See Appendix 13). Service user and carer perspectives should be built into rehabilitation trials (Sinclair and Dickinson 1998) in order to tap into outcomes of service provision that cannot be determined by standardised measures alone. The way forward for research in domiciliary physiotherapy is discussed at the end of this chapter.

3. DISCUSSION OF THE PROCESS OF DOMICILIARY PHYSIOTHERAPY

Challenges faced by the DPS staff as they moved through the phases of ‘transition’, ‘settling in’ and ‘emergence’ were discussed in Chapter Five. ‘Knowledge and expertise’, ‘models of practice’ and ‘power and control’ emerge from the literature as concepts which might explain why therapists based previously in hospitals found it challenging to move into community practice. This section will discuss each of these concepts in turn, from the perspectives of theory and practice.

3.1 KNOWLEDGE AND EXPERTISE

In the context of professional practice, knowledge must be regarded as a value-laden entity (Higgs and Titchen 1995). Individual therapists will interpret the same information in different ways, according to their personal view of the world, and the multiple realities within which they practice. Their perspectives on a situation will be influenced by how they think other people (including clients and carers) see that situation. Such multiple perspectives (Heyman 1995a) are not fully open to conscious awareness, and greatly influence the practitioner’s personal frame of reference. The domiciliary physiotherapists in the trial came to their new jobs with knowledge built up over years of physiotherapy practice in mainly hospital environments.

However, they could not always usefully apply their previous knowledge to their new situation. To understand why staff found the early days of domiciliary practice difficult, one must view knowledge as context-specific, rather than context-free (Higgs and Titchen 1995). Their new work environment demanded of the DPS staff an awareness of social, cultural and behavioural components of disability, which are often hidden when patients are in institutional environments. Patients usually comply with advice and instructions whilst in hospital in order to facilitate their discharge home. However, once they are in their own environment, they may become more concerned with long-term management of their disabilities. For example, a carer may be experiencing increasing difficulty in moving and handling his or her relative who is becoming progressively weaker. When hospital staff need to physically lift a patient, a hoist is introduced. However, the presence of a mechanical hoist in the home may be socially and emotionally unacceptable. Although it may make it physically easier for the carer to cope, a hoist takes up a great deal of space and is a visible reminder to everyone in the home that the disabled person can no longer move themselves. For the client, the experience of being carried through the air in a sling can be very frightening when they are used to being manually lifted by a person whom they trust.

In their previous jobs, staff probably worked with undelimited claims to expertise (Heyman and Henriksen 1998), feeling able to give concrete advice, based on the assumption that they and their patient shared the same aims. However, the undelimited model of expertise breaks down when professionals and clients have different aims. In community-based practice, the therapist must first find out what the client's own goals are before starting to plan and implement therapy. For example, the client may not understand, or comply with, exercises to improve lower limb muscle strength and range of movement unless they are part of an agreed strategy to help him fulfil his wish to be able to climb stairs to bed at night instead of sleeping in the living room. Valuing the client's knowledge and experience is an important antecedent to

empowerment (Rodwell 1996). Physiotherapists have much to learn from clients with progressive conditions who have developed their own ways of coping.

As the trial progressed, the domiciliary physiotherapists constructed new professional craft knowledge and, after a time, were able to draw on their experience to predict outcomes and select therapeutic options. They were able to weigh up social cues, such as the interaction between a carer and client, before automatically involving the carer in the client's rehabilitation programme. As the need to consciously analyse a situation lessens, the practitioner can be said to be using intuition. Benner (1984) argues that intuition is based upon a broad base of knowledge and experience, and is only available in situations where a deep background understanding exists. Parry (1997) further argues that informal intuitive knowledge in physiotherapy is undervalued and under-researched. However, Paley (1996) questions the basis upon which intuitive judgements are made. He argues that so-called intuition could just as easily be whim or guess work and asks the question, do *all* experts and *only* experts use intuition? There are no independent criteria against which to evaluate intuitive judgement, and Paley worries that the kind of expertise associated with intuition may be constraining if the practitioner becomes locked into expert 'habits' of thought.

The current drive for evidence based practice poses dilemmas for therapists whose practice is underpinned by professional craft knowledge and intuitive reasoning. In community-based practice, client and carer problems are rarely straightforward. As well as having multiple sclerosis, the client may have the added problem of an acute chest infection at a time when their carer is suffering a flare-up of arthritis. Neither research-based nor craft-based knowledge is enough on its own in such a unique constellation of circumstances. General evidence-based solutions may not work, and wise practitioners will need to make best use of both their intuitive and conscious reasoning skills, to analyse the problems and test out various therapeutic options. The skills and attributes required in an expert domiciliary physiotherapist are not easily

articulated. The voyage of the DPS staff through the turbulent seas of community-based practice has thrown up some difficult issues of knowledge and expertise not yet grasped by the physiotherapy profession. Helping someone to cope with a life-long problem through home-based intervention requires not only an organised knowledge base and well developed reasoning capability on the part of the practitioner, but also a deep understanding and regard for the knowledge and expertise of the client and carer. Expert community-based practice requires a therapist to have perspectives not yet core to the undergraduate physiotherapy curriculum, such as in-depth knowledge and experience of models of practice other than medical.

Even at post-registration level, courses mainly offer opportunities to acquire new knowledge and therapeutic skill in movement, manipulative or electrical therapy. They rarely address issues such as how to use and apply knowledge, or how to adapt an approach within non-institutional settings. The simple act of acquiring knowledge does not equip the practitioner to know when or how to apply that knowledge to client care (Richardson 1992a). Despite the high level of decision making and organisational skill involved, domiciliary practice does not hold high status as a career pathway in physiotherapy. Ironically, areas that physiotherapists do regard highly with respect to career progression, such as acute hospital practice, are the very ones where physiotherapists work more under doctors' control and direction (Robinson 1988). Many physiotherapists do not want to work in care of the elderly, and managers of services may assume they cannot recruit staff because working with older people lacks challenges and requires little expertise. However, Finn (1986) has shown that the lack of medical support and high level of autonomy which physiotherapists working with older people experience may explain why some do not want to work in geriatric care. The same lack of association with doctors, and the challenges of independent decision making, may also explain why many therapists do not choose domiciliary practice. The next two sections of this chapter, on models of practice and power and control, will further explore the issue of professional status. In the

following section, the relevance of the medical model will be discussed in relation to community-based practice.

3.2 MODELS OF PRACTICE

Moving out into primary health care was a significant challenge for physiotherapy practitioners trained for and accustomed to a medicalised institutional working environment. Since the foundation of the Chartered Society of Physiotherapy, in the late nineteenth century, physiotherapists have held a strong allegiance to medicine. To gain respectability the founders of the profession invited the patronage of doctors. Many physiotherapists viewed association with medicine as something to be welcomed and cultivated, as doctors form one of the most powerful groups in society. However, medical paternalism left a legacy in the form of a physiotherapy profession that has moulded itself on medicine (Sim 1990, Roberts 1994). Physiotherapists have developed treatments and approaches based on tenets of the medical model. For example, much of physiotherapy is based on the medical concept of ‘normality’. Therapists are trained to recognise normal ranges of movement, normal patterns of movement and normal levels of functional ability (Roberts 1994), and classical physiotherapy treatment aims to restore any abnormal movement or function to within a normal range. Physiotherapy deals primarily with disorders of the body, using physical means, largely ignoring the role of psychological factors in the causation or progression of physical problems. Exclusion of the mind or mental events as possible causes of physical events is known as ‘epiphenomenalism’ (Milner 1998). Physiotherapists are taught that the human body can be reduced or broken down into constituent parts and that each part behaves according to physical laws. Practitioners acquire distinctive technical skills, such as manipulation or movement facilitation, that can be applied to particular parts of the body to correct deformity, improve range and quality of movement or reduce local pain. Physiotherapy courses do not teach students to consider psychosocial factors, such as bereavement or stress, as possible causes of physical problems.

However, in some cases treated by the DPS staff, the reason for referral was arguably psychosocial, e.g. *loss of confidence, gone off legs, unable to leave the house*.

Within the context of community care for long-term disability, medical model concepts such as 'normality' and 'epiphenomenalism' become problematic. Early in the DPS trial, the staff struggled to see the relevance of physiotherapy when movement could not be restored to normal, and the specific cause of the movement disorder could not be eradicated. They found it particularly difficult to decide when to terminate treatment, especially when the results of their intervention could not be observed in the usual way, e.g. through measurement of improved range of movement or increased muscle strength. Feelings of indecision about when to stop treating the client may well have reduced the domiciliary physiotherapists' sense of control over their work. In hospital-based physiotherapy, intervention often has a definite end point, such as when the patient is discharged from hospital. In the community, it is very difficult for therapists to identify an end-point when they can see that the client and carer must continue to live with long-term disability or progressive disease. Other authors have reported on the difficulties associated with trying to offer a time-limited course of physiotherapy to clients with chronic progressive conditions (Furnell and Furnell 1987). Robinson (1988) suggests that physiotherapists experience difficulty in adapting to long-term rehabilitation because their role is traditionally geared towards brief discrete interventions in acute medical environments. Furthermore, Finn (1986) found that physiotherapists were reluctant to work in geriatric care because of the multiple and chronic nature of patients' problems and the difficulty of measuring and achieving a successful outcome. Being able to take the decision to terminate treatment is also a feature of the power that the therapist has over the client (Hugman 1991), as well as the product of a particular model of practice.

Using technical intervention to cure a problem or restore someone to 'normal' is a key feature of medical model practice and assumes high status in physiotherapy (Alaszewski 1979). In the

early part of the trial, staff were frustrated by the mismatch between what they had to offer, as skilled technical practitioners, and the expectations of the client for a less medical approach. Later, the DPS staff began to see the value of non-technical interventions. The provision, for example, of a simple piece of equipment, such as a walking aid or commode, became part of a more humanistic style of intervention from which therapists gained satisfaction.

The DPS staff gradually and intuitively shifted to a more psychosocial model of practice. They began to recognise that normality is as much socially and culturally defined, as it is medically determined. For example, the lived experience of a trial client who had arthritis was more influenced by her positive attitude to life and her determination to keep mobile than it was by the constant pain she suffered or the range of joint movement she had lost. The perspectives of staff widened, as they gained experience, and their priorities shifted to include social and psychological dimensions of health. Clients' problems can not be unambiguously diagnosed, as medical model reasoning would suggest. They have to be interpreted through a complex process of problem framing (Schon 1991). The DPS staff no longer expected a client's problems to fit into their way of thinking, and they stopped measuring physical ability against pre-determined norms. Instead, they began to recognise the client's own view of their situation, and their individual responses to their problems, and to take these into account when deciding treatment goals and techniques. Negotiation with clients about treatment goals not only represented a shift in model of practice, but also a shift in the balance of power towards a more equal therapist-client relationship. Qualitative data from clients and carers indicated that they valued the social and emotional support given by therapists as much as the physical treatment and practical advice.

A number of groups within the physiotherapy profession are widening their thinking beyond traditional medical theories and many physiotherapists would claim that they now practice in a holistic way (Roberts 1994). According to Milner (1998) holism can be understood in two

ways. Firstly, it can refer to the traditional view of human beings as integral parts of an ordered system of nature. Secondly, the concept of holism has evolved into a view that all parts of the body interact, and that the functioning of one element should not be considered in isolation of another. In a physiotherapy assessment, the practitioner will take account of the client's problems from physical, psychological and social perspectives. However, in treatment, they are likely to consider each perspective separately, rather than as interdependent components of the whole person. When dealing with a stroke patient who is depressed because they cannot go out or climb stairs, they may acknowledge the emotional and social problems by referring on to Social Services for assessment for home adaptations and a place in a day centre. Physiotherapy treatment will then focus on correction of the movement disorder caused by the stroke. The practitioner will probably not consider the impact of the client's depression and social isolation on the extent and progression of that movement disorder. While perspectives other than physical are recognised by physiotherapists, they are unlikely to see these perspectives as being either amenable to physiotherapy intervention or intrinsically linked to the physical problem. What physiotherapists claim as holism is more likely to be a metaphorical physical, psychological and social deconstruction of the patient, followed by a reconstruction when these individual components have been treated (Alaszewski 1979).

Physiotherapists can not be all things to all people. The treatment of physical problems through physical means will remain at the heart of physiotherapy and define its distinctiveness as a profession. Modern health and social care involves multiple different agencies, which should be capable of dealing with the multiple needs of clients and carers. The lesson for domiciliary physiotherapy practitioners may be that their distinctive physical approach needs to be flexible and tailored to each individual within the context of their own social and psychological needs and expectations. The impact on physical problems of all aspects of a client's functioning need to be properly considered, not just acknowledged and passed on. To be effective, domiciliary physiotherapy practice should be informed by models other than that of medicine, which has

dominated physiotherapy development for over one hundred years (Ovretveit 1985). The complexity and uniqueness of community-based physiotherapy practice may require a new model. An approach which acknowledges that therapy involves *exchange* of ideas, rather than one-way transfer of expertise from practitioner to client, has been applied to family therapy (Andersen 1987). Andersen's 'reflecting team' model emphasises that professionals and clients can learn from each other. The idea of mutual learning in therapeutic encounters has been used to underpin a 'reciprocal learning' model of domiciliary physiotherapy which will be presented later in this chapter.

3.3 POWER AND CONTROL

Physiotherapy has been afforded high status within the remedial therapy professions, by virtue of its command of technical skill and its close association with medicine (Alaszewski 1979). Within the physiotherapy profession, the majority of people progress up the career ladder by developing expertise and specialist knowledge in medically defined areas of practice, e.g. orthopaedics, neurology or surgery. Senior physiotherapists are viewed by themselves and their peers as specialists possessing a substantive field of knowledge, mastery over the application of that knowledge and a high level of technical skill applicable to patients' problems *only* in that area (Ovretveit 1985). In the 1970s, the profession shrugged off medical dominance to achieve long fought for clinical autonomy. However, physiotherapy emerged from doctors' control not as a patient-centred but as a technique-centred service (Alaszewski 1979), still ideologically dominated by medicine. The assumed role of the patient remained passive within the therapist-patient relationship, and physiotherapists viewed themselves as experts who knew best. In the DPS trial, staff initially felt uncomfortable, as they were not 'in control' of the interaction between them and the client.

According to Hugman (1991), there are many subtle factors that contribute towards professional control. For example, referring to patients by their diagnosis, as in "Mrs. Smith is a

stroke”, depersonalises the patient and removes their identity as an individual. For clients in the DPS trial, medical labels were often difficult to ascribe. Clients had to be seen as individuals with a complexity of problems, which were difficult to pigeonhole and could only be understood in their social context. In the community, therapists do not have their own department and there are no areas that are out-of-bounds to clients. Their work environment is the client’s home, which means they are always guests in someone else’s ‘space’. The client can not be asked to leave and the therapist has nowhere to retreat to during the course of a treatment session. This position reduces, for professionals, the sense of power that comes from owning the environment (Hugman 1991).

In the community, clients become empowered to some extent if they develop skills that enable them to use services strategically and selectively to achieve their own objectives (Heyman 1995b). In community midwifery, it was found that mothers who chose to give birth at home took more decisions regarding when to have their membranes ruptured than most midwives in consultant delivery units (Kirkham 1989). According to Labonte (1994) professionals must learn to share power *with* the patient rather than attempting to assume power *over* them. However, moving from models of professional control to accepting patient empowerment requires physiotherapists to take a fresh look at themselves and how they respond to patients’ needs (Parry 1997). Domiciliary physiotherapists must learn to relinquish the paternalistic power of the caring role (Rodwell 1996) for partnership with their client. As we move to a more consumer orientated health system, clients expect to be offered choice in their treatment, and to be treated as individuals. Consequently, physiotherapists, like many other professionals, now make claims to partnership and collaboration with clients.

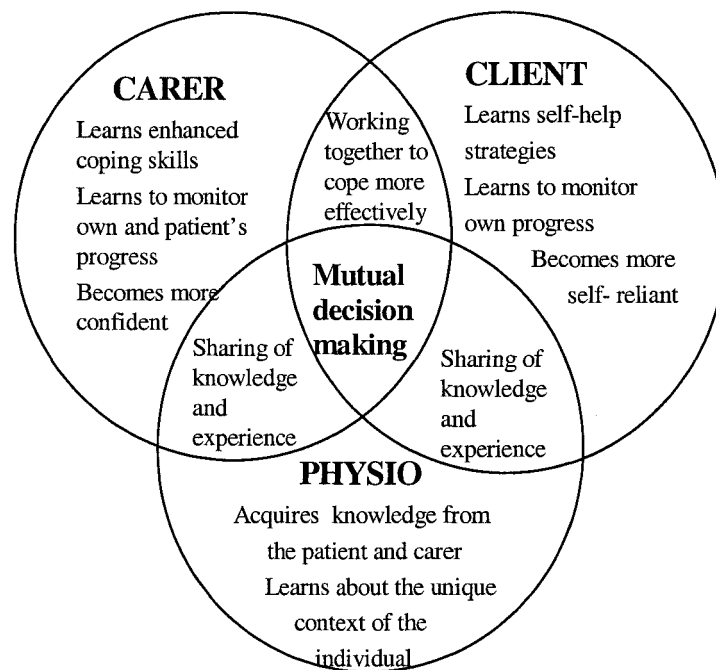
The realisation that they were still doing their job by responding to individual clients’ needs and expectations, rather than prescribing to clients how they should live their lives, was a professionally liberating transition for some DPS staff. Practice which recognises power

sharing will be taken up more readily by clients, whilst undelimited approaches will be rejected as soon as clients begin to question professional expertise or values (Stacey 1976). As previously mentioned, valuing the patient's knowledge and experience is an important antecedent to empowerment (Rodwell 1996). In a therapist-patient partnership, treatments and self-help strategies can be offered as new options for consideration, not as instructions to be followed. Approaches that recognise the patient as the primary producer of his/her own health (Stacey 1976), and minimise dependency, should be promoted. It is expedient to encourage the patient and carer to take control of their own problems, as resources do not allow treatment to be continued indefinitely. For example, in the later stages of stroke rehabilitation, there is little benefit for the patient if the movement they gain under the skilled hands of the therapist cannot be reproduced in their daily lives. Educational approaches that help patients and carers acquire new coping skills and positive attitudes may be more appropriate for later stage patients being cared for in a domiciliary setting. For example, carers of disabled people can be taught effective and safe handling skills, which they can use long after the physiotherapy intervention has ended. Clients with progressive conditions can be shown how to maintain their own physical function for as long as possible, through appropriate self-management strategies such as exercise or natural pain relieving methods.

3.4 A RECIPROCAL LEARNING MODEL OF DOMICILIARY PHYSIOTHERAPY

Figure 16 shows a diagrammatic model of domiciliary physiotherapy that has been developed from the interpretive analysis of the process of domiciliary physiotherapy. The model is based on a concept of 'reciprocal learning', within which all parties acquire unique knowledge and skill. The client, carer and physiotherapist are represented as overlapping circles and text in each circle summarises possible outcomes for each party. For simplicity, other members of the multidisciplinary team are not shown. However, in practice, other professionals, e.g. District Nurses, Occupational Therapists or GPs, may map onto the model by interacting with any one, or two, or all three of the physiotherapist, the client, and the carer.

Figure 16
The reciprocal learning model of domiciliary physiotherapy



The model takes into account practitioner, client and carer perspectives. Where appropriate, the client may become more self-reliant through learning self-help strategies. Both the carer and client may learn how to monitor their own progress and the carer may feel more confident. Together, the client and carer may manage to cope more effectively with the client's long-term problem. In the reciprocal learning model, individualised intervention can only be offered if the domiciliary physiotherapist has learned about the unique context of the client and carer. Successful outcomes are dependent on interaction between all the key players. The client, carer and physiotherapist work as a team, sharing knowledge and experience. Mutual decision making, symbolised by the central area where all three circles overlap, forms the core of the model.

4. CONCLUSION AND IMPLICATIONS FOR THE FUTURE

This thesis has presented the results of a randomised controlled trial, which has demonstrated non-significant, yet clinically important, effects of domiciliary physiotherapy on clients' physical mobility and performance on stairs. Exploratory analysis has yielded possible hypotheses for future research in relation to the role of a DPS in reducing the need for day hospital and respite care. The introduction of domiciliary physiotherapy has been shown to lead to a greater likelihood of clients gaining access to other community based services, through physiotherapists referring on to other colleagues, although GPs may refer-on less frequently. These results are original, in that there are no other published trials of a generic domiciliary physiotherapy service. Results from well-conducted RCTs are key to the advancement of evidence based practice in health care. Although the trial has not generated conclusive evidence about the cost-effectiveness of domiciliary physiotherapy, there are important reasons for making public it's results. Other researchers could design new trials to test the validity of the exploratory findings. However, now that domiciliary physiotherapy services are embedded in mainstream practice, random allocation of clients to control groups may be problematic ethically. In the future, results of multiple trials could be brought together in a meta-analysis, which, by increasing sample size, might improve the power of statistical tests to detect significant differences.

The reflexive analysis of the physiotherapists' transition from hospital to domiciliary practice could offer an important contribution to the body of knowledge of physiotherapy, as the challenges in role adaptation are more complex than may be assumed. As we move towards primary care-led services, the preparation of undergraduate therapists for community-based work will require a broad-based curriculum and a shift in attitude towards holistic practice. New entrants to the profession need to leave universities mindful of their responsibility to facilitate clients' and carers' self-empowerment. However, they may not easily find role models in practice who have truly encompassed a shift towards such client-centred practice, as

continuing professional development and career structure for qualified practitioners seems to be heavily focused on skills-based competencies. The term 'extended' practitioner has been used to describe a new high status 'clinical specialist' physiotherapist who has been trained to take on functions previously reserved for doctors, such as giving intra-articular injections and prescribing certain medications. The accomplished generalist domiciliary physiotherapist has also extended his or her practice, but more in terms of advanced client-centred decision making and reasoning capacity than practical skill. Such practitioners may lead the way in terms of their ability to integrate the worlds of medical and personal knowledge, but there are no 'clinical specialist' posts in domiciliary practice and no special term or career ladder which acknowledges the level of accomplishment of the generic practitioner. Physiotherapy operates within a strongly science-based culture that values and rewards specialist technical expertise, which, by definition, must be narrow and focused. The contribution of this thesis to the continuing development of the physiotherapy profession may therefore lie in the recognition it gives to the expertise of the generalist domiciliary practitioner.

The reciprocal learning model of domiciliary physiotherapy, which was derived, in part, from the incidental knowledge and experience so often disregarded in randomised controlled trials, may help physiotherapists to work more effectively in the home situation with clients and carers who are coping with long-term disability. The concept of reciprocal learning challenges traditional approaches by valuing the knowledge and expertise of the client and carer as highly as that of the therapist. The players in the model interact in ways that facilitate client and carer self-reliance and coping, rather than dependence on the therapist, in order to achieve long-term benefit. The domiciliary physiotherapist can then withdraw from the case having left something useful behind. What he or she 'leaves behind' may be a client and carer who manage disability more effectively, rather than a less disabled client. The reciprocal learning model now needs to be tested out by practitioners, so that it's transferability beyond the context and time frame of the DPS trial can be evaluated. Domiciliary physiotherapy services have flourished in the UK

over recent years, providing ample settings for further research. Observational studies of practice could be conducted in order to investigate the credibility of the model in contemporary practice, and there is considerable scope for dialogue with today's domiciliary practitioners about the challenges of their practice.

If the real benefits of domiciliary physiotherapy relate to the enhancement of client and carer self-reliance, it may not be surprising that the RCT failed to show substantial effects as measured by scales of activities of daily living and health status. Measures of the outcome of domiciliary physiotherapy should evaluate the ability of the client and carer to manage their own health problems, rather than quantify the resolution of those problems. In the current climate of evidence-based practice, we may move to a position of withdrawing therapy when outcomes cannot be determined, and trials have not 'proved' that therapy is worthwhile. Before we get to the position of allocating resources to therapy on the basis of evidence, we need to start re-framing the way in which we develop that evidence. Domiciliary physiotherapy service providers should interact with clients and carers to establish their needs and negotiate how those needs may be met. Researchers should acknowledge that measurable outcomes can not easily be determined. Qualitative studies, which investigate client and carer perspectives, may provide a useful starting point for the selection of criteria for assessing the effectiveness of domiciliary physiotherapy. Thus, future trials could be improved by, firstly, starting from an understanding of the process of the intervention being tested, and, secondly, by using more relevant, informed outcome measures.

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APPENDIX 1

PROJECT ADVISORY GROUP

The project was designed and monitored by an advisory group made up of local researchers with expertise in various fields. They are listed below by their name and work title at the time of the trial.

Mrs. Sylvia Hogarth, Director of Newcastle Physiotherapy Services.

Dr. Barbara Gregson, Statistician, Centre for Health Services Research, University of Newcastle upon Tyne.

Prof. John Bond, Director, Centre for Health Services Research, University of Newcastle upon Tyne.

Dr. David Parkin, Health Economist, University of Newcastle upon Tyne.

Dr. Pauline Pearson, Research Nurse, Unityne Health.

Dr. Rowena Plant, Senior Lecturer, Institute of Health Sciences, University of Northumbria at Newcastle.

Dr. Judith Hooper, General Practitioner (group member from 1989 to 1991).

Dr. Martin Eccles, General Practitioner, Director of Primary Health Care Research, Centre For Health Services Research, University of Newcastle upon Tyne (group member from July 1993 to Sept 1993).

APPENDIX 2

GUIDELINES FOR GENERAL PRACTITIONERS

NEWCASTLE HEALTH AUTHORITY

SAIMSBURY TRUST ADULT COMMUNITY PHYSIOTHERAPY PROJECT

INFORMATION FOR GENERAL PRACTITIONERS I

1. AIM

To evaluate the impact of a Community Physiotherapy Service (C.P.S) by comparing Community Physiotherapy intervention with existing care for adults and their carers

2. DEFINITIONS/NOTES

- i. Community Physiotherapy is physiotherapy assessment/management/treatment undertaken in any setting other than a hospital or day hospital.
- ii. This setting may be the client's own home, a local authority or private residential home, or a local authority day centre.
- iii. The physiotherapy management of the client's problems may include educating or advising their carers on matters specific to that individual.
- iv. These carers may be informal e.g. relatives, friends, or formal e.g. care attendants, nurses.
- v. For the purposes of this project, Community Physiotherapy does not include group education of carers on a non-individual client related basis. However, it is hoped that some indication of the need for this will emerge as part of this initial evaluation.
- vi. For the purposes of this project, Community Physiotherapy does not include group management/treatment of clients. However, it is hoped that some indication of the need for this will emerge as part of this initial evaluation.
- vii. The physiotherapist will determine the nature and duration of any management/treatment to be given; or may decide, after assessment, that physiotherapy intervention is not appropriate.
- viii. In some cases, the physiotherapist may seek the opinion of other members of the multi-disciplinary team.
- ix. In all cases feedback will be given to the G.P.

3. INCLUSION CRITERIA

1. Men and women aged 18 and over resident within the boundaries of Newcastle Upon Tyne Health Authority and referred to the C.P.S by their G.P.

4. EXCLUSION CRITERIA

1. Clients with an identified mental handicap who are already under the care of the Community Mental Handicap Team.
- ii. Clients with an identified mental health problem who are already under the care of one of the Mental Health Area Teams.

5. WHO TO REFER

Please inform your clients G.P if you feel a Community Physiotherapy assessment is indicated since all referrals must come via this route.

However, you may find the following guidelines helpful when identifying the need for Community Physiotherapy

1. Clients who would find travelling to hospital for Out-patient Physiotherapy difficult/stressful/impossible, and where this would negate any benefits received from out-patient treatment.
2. Clients whose problems are so intrinsically linked to the home environment that treating out of this setting would be inappropriate.
3. Where treating in the Community is the best way to facilitate education/support of formal or informal carers where this must form an important part of the client's management.

Please do not refer clients who would be able to travel to hospital for out-patient physiotherapy and who would significantly benefit from facilities/specialist treatment available in these departments.

Until open access to hospital out-patient physiotherapy departments is available for all G.P.'s you should continue to refer these clients to consultants.

6. HOW TO REFER

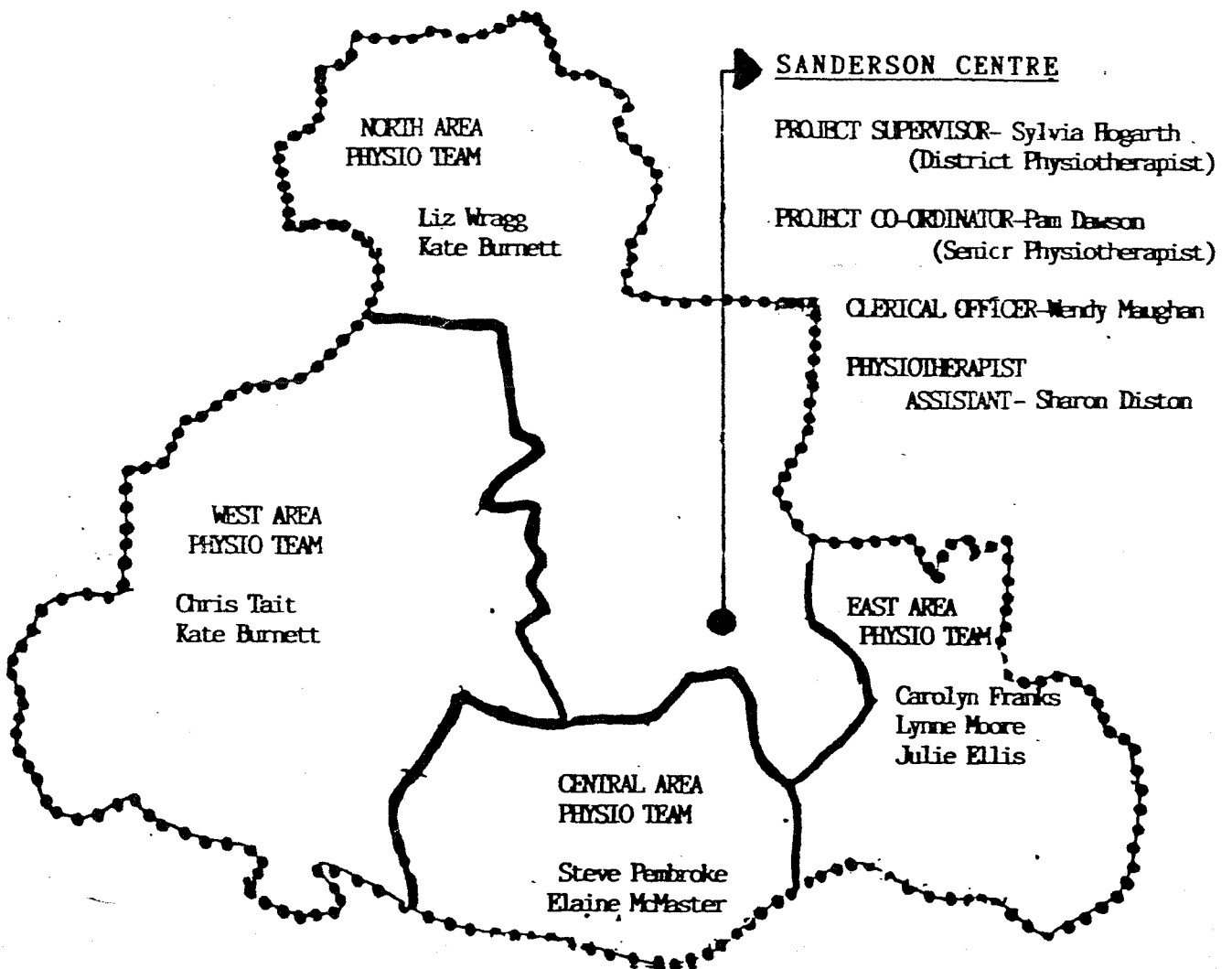
You will be provided with referral forms. Please complete these in full and return them to

Community Physiotherapy
Sanderson Centre
North Avenue
GOSFORTH (Courier code: H13)
Tel: 2852315 /2131972.

In urgent cases, where assessment is required quickly you may make a referral over the telephone before sending on the form.

Over the course of the next few weeks you will be visited by a member of the Physiotherapy Team for the area in which your Practice is located (see map).

If you require further information before then please contact Pam Dawson (Research Co-Ordinator) at the Sanderson Centre.



TO THE COMMUNITY PHYSIOTHERAPY SERVICE

RESPIRATORY

1. Acute Acute respiratory infections
 acute bronchitis
2. Chronic chronic bronchitis
 asthma
 bronchiectasis
 emphysema
3. Terminal Ca. Lung
 respiratory complications of neurological problems
 eg in M.N.D

RHEUMATOLOGY/ORTHOPAEDICS

Community Physiotherapy services for this group will be most appropriately used where problems are linked to function and long-term management.

With regard to back and neck problems this means that in the absence of radiological back up and specialist equipment, the community physiotherapist's role is one of education.

Please remember that people who can travel to hospital or the Sports Injury Clinic and who would significantly benefit from these Out-patient Physio-therapy facilities should continue to be referred via existing routes (eg referral to Consultant).

Examples of appropriate conditions:

1. Degenerative joint disease eg R.A., O.A.
2. Mobility problems eg post orthopaedic surgery
general deteriorating function
3. Immobility problems eg post trauma - following a fall
general debility/"off feet" syndrome.

NEUROLOGY

1. Stroke
 - a) **Recent stroke**

Where it is hoped that the client can remain at home, early referral to the Community Physiotherapy Service is essential.
 - b) **Previous stroke**

Where there are residual problems a Community Physiotherapy assessment will highlight the need for either treatment and/or advice/counselling
2. Parkinsonian syndromes
3. M.S.
4. M.N.D.

APPENDIX 3

GP INFORMATION PACK

SAINSBURY TRUST ADULT COMMUNITY PHYSIOTHERAPY PROJECT

NOTES FOR G.P's RE: RANDOMISED CONTROLLED TRIAL

1. As from now, all referrals to Adult Community Physiotherapy will be randomised into one of two groups:

1 = The **TRIAL GROUP**

2 = The **CONTROL GROUP**
2. After following the procedure for obtaining INFORMED CONSENT (see sheet) you should ring the referral through to Community Physiotherapy between 8.30 am - 4.30 pm on the following number only **2131972**
3. You will be informed immediately which group the client has been randomly allocated to, and you will be given a **SURVEY NUMBER**. Please enter this onto the Yellow Referral form (in the top left hand corner, in the boxes provided) and onto the small Record Booklet. The survey number will end in either a 1 or 2. This will enable you to keep account of which group your patients are in.
4. Please fill in the top half of the first page of the Record Booklet and then inset it into the patients medical records. This Booklet should then be updated regularly.
5. **NB** In the case of urgent referrals who are allocated to the Trial Group you may give the necessary medical information over the phone at the time of randomisation.

However please remember to send on the yellow form for **ALL** referrals, whether trial or control.

If you have any further queries, please contact me on 2852315 or 2131972.

THANK YOU FOR YOUR CO-OPERATION

Pam Dawson MCSP
Research Co-Ordinator
Sainsbury Trust Adult Community Physiotherapy Project

NEWCASTLE HEALTH AUTHORITY

SAINSBURY TRUST ADULT COMMUNITY PHYSIOTHERAPY PROJECT

NOTES FOR G.P.'s RE: PROCEDURE FOR OBTAINING INFORMED CONSENT

After identifying the client as an appropriate referral to Adult Community Physiotherapy the G.P. should

1. State that she/he is currently involved in a study to assess the way services are provided in the Community.
2. Ask the client if she/he is willing to take part in the study, which will involve them in:
 - a) Being allocated to one of two groups which receive different services (One of the services could be Community Physiotherapy)
 - b) Being visited at intervals for approximately eighteen months by a research worker
3. The G.P should then offer the client the information sheet which outlines the purpose of the Project.
4. At this time the G.P should state that if the client does not want to take part, that he/she will still have access to all existing services (but not Adult Community Physiotherapy)
5. If the client agrees, the G.P must then ask for written consent, on the form provided giving reassurance of confidentiality and that the client can withdraw at any time. (Please keep completed forms at the Practice in the folder provided.)
6. After agreement, the G.P can then refer the client for randomisation, by ringing Community Physiotherapy on 2131972 between 8.30 am - 4.30 pm.

NEWCASTLE HEALTH COMMUNITY PHYSIOTHERAPY SANDERSON CENTRE

caring is our concern

NORTH AVENUE
GOSFORTH
NEWCASTLE UPON TYNE
NE3 4EL
Telephone TYNESIDE (091) 285 2315

Your Ref:

Our Ref:

Sainsbury Trust Adult Community Physiotherapy Project

Client Consent Form

I consent to participate in the above project, which will involve me being visited at intervals during the next eighteen months, and information being collected about my health.

This information will be kept in the strictest of confidence and will not be published in relation to individuals at any time.

I agree to the research team having access to my medical records.

I understand that I can cease to participate at any time.

FULL NAME

ADDRESS

SIGNATURE DATE

NEWCASTLE HEALTH COMMUNITY PHYSIOTHERAPY SANDERSON CENTRE

caring is our concern

NORTH AVENUE
GOSFORTH,
NEWCASTLE UPON TYNE
NE3 4EL.
Telephone: TYNESIDE (091) 285 2315

Your Ref:

Our Ref:

INFORMATION FOR CLIENTS

This important study is being conducted by Newcastle Community Health Unit, to assess the impact of a Community Physiotherapy Service as part of the total range of services available to people in Newcastle.

People who take part in the study will be allocated to one of two groups who will receive different services. These services may or may not include physiotherapy. All people in the study will be contacted at intervals for a period up to 18 months, in order to follow their progress.

Information will be needed on their contacts with people from the Health Authority and Social Services and whether or not they are admitted to Hospital at any time. The research team will provide a record sheet to be kept by people at home.

In addition, the research team will interview people in the study 3 times in 18 months about how they are coping with everyday activities and how they feel about their life and health in general.

The research team would appreciate having access to the medical records of people in the study.

All information collected will be kept in the strictest of confidence, and will not be published in relation to individual people.

NEWCASTLE HEALTH AUTHORITYSAINSBURY TRUST ADULT COMMUNITY PHYSIOTHERAPY PROJECTREFERRAL FORM

Please complete **ALL** sections in **BLOCK LETTERS** and delete where necessary.

Date of referral

Patients SURNAME Mr/Mrs/Miss Marital Status S/M/W/
Other

FORENAMES DOB

Address

.....

..... Tel no

G P Name Hospital Consultant

G P Signature GP Tel no

Medical Diagnosis

.....

Reason for referral

.....

Other relevant information

.....

Current Medication

.....

Is the patient currently receiving Physiotherapy - YES/NO If yes, please tick boxes and state where.

Out-patient physiotherapy department

Day Hospital/Clinic

Private

Has the patient received physiotherapy for the same problem during the past 12 months - YES/NO If yes, please tick boxes and state where.

In-patient

Out-patient physiotherapy department

Private

Community

Day Hospital/Clinic

APPENDIX 4

BARTHEL INDEX SCORING GUIDELINES

The BARTHEL ADL Index

DATE

MOBILITY

- 0 = immobile
- 1 = wheel chair independent including corners etc.
- 2 = walks with help of 1 person (verbal or physical)
- 3 = independent (but may use any aid, e.g. stick)

TRANSFER

- 0 = unable
- 1 = major help (1-2 people, physical)
- 2 = minor help (verbal or physical)
- 3 = independent

STAIRS

- 0 = unable
- 1 = needs help (verbal, physical, carrying aid)
- 2 = independent up and down

BLADDER

- 0 = incontinent or catheterised & unable to manage
- 1 = occasional accident (max 1x per 24 hours)
- 2 = continent (for over 7 days)

BOWELS

- 0 = incontinent
- 1 = occasional accident
- 2 = continent

TOILET USE

- 0 = dependent
- 1 = needs some help, but can do something
- 2 = independent (on & off, dressing, wiping)

FEEDING

- 0 = unable
- 1 = needs help cutting, spreading butter etc.
- 2 = independent

DRESSING

- 0 = dependent
- 1 = needs help, but can do about half unaided
- 2 = independent

GROOMING

- 0 = needs help
- 1 = independent, face / hair / teeth / shaving

BATHING

- 0 = dependent
- 1 = independent

TOTAL

APPENDIX 5

INTERVIEW SCHEDULE

Initials of fieldworker Survey no

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CONFIDENTIAL INFORMATION

NEWCASTLE HEALTH AUTHORITY

SAINSBURY TRUST ADULT COMMUNITY PHYSIOTHERAPY PROJECT

1. Date of interview

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2. Tick if the client in Residential Care Soc Services
Private

If Y, ask Q 3,4, and 6 only on this page.

3. Is the client male or female

M
F

4. What is your date of birth

--	--	--	--	--	--	--	--	--	--

5. Do you live alone?

Y
N

6. Does the client have communication difficulties?

Y
N

7. Is there one person (other than a D. Nurse or outside care
assitant) who helps with day to day activities such as getting
around the house, getting up and going to bed, getting
dressed, washed, going to the toilet, feeding etc?

Y
N

If Yes, Q 8, if No, Q 11.

8. Who is this person?

husband/wife
parent
daughter/son
other relative
friend
other

If other please specify

9. Is this person male or female

M
F

10. Does this person live with you?

Y
N

11. Do you have a home help?

Y
N

If Yes - How often

(write down)

--

12. Do you have any care attendents or care
assistants visiting the Home?

Y
N

If Yes How often?

(write down)

--

Which agency or where do they come from

(write down)

--

--	--	--	--	--	--	--	--	--	--

1.

CONFIDENTIAL INFORMATION

LISTED BELOW ARE SOME PROBLEMS PEOPLE MIGHT HAVE IN THEIR DAILY LIVES.

READ THE LIST CAREFULLY AND PUT A TICK IN THE BOX UNDER YES FOR ANY PROBLEM THAT APPLIES TO YOU AT THE MOMENT. TICK THE BOX UNDER NO FOR ANY PROBLEM THAT DOES NOT APPLY TO YOU.

PLEASE ANSWER EVERY QUESTION. IF YOU ARE NOT SURE WHETHER TO ANSWER YES OR NO, TICK WHICHEVER ANSWER YOU THINK IS MOST TRUE AT THE MOMENT.

	YES	NO
I'm tired all the time	<input type="checkbox"/>	<input type="checkbox"/>
I have pain at night	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I take tablets to help me sleep	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
Things are getting me down	<input type="checkbox"/>	<input type="checkbox"/>
I find it painful to change position	<input type="checkbox"/>	<input type="checkbox"/>
I'm feeling on edge	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I feel lonely	<input type="checkbox"/>	<input type="checkbox"/>
I can walk about only indoors	<input type="checkbox"/>	<input type="checkbox"/>
I have unbearable pain	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I find it hard to bend	<input type="checkbox"/>	<input type="checkbox"/>
Everything is an effort	<input type="checkbox"/>	<input type="checkbox"/>

Please turn over

2. CONFIDENTIAL INFORMATION

Survey no

--	--	--	--	--	--	--	--

	YES	NO
I'm unable to walk at all	<input type="checkbox"/>	<input type="checkbox"/>
I'm waking up in the early hours of the morning	<input type="checkbox"/>	<input type="checkbox"/>
I've forgotten what it's like to enjoy myself	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I'm finding it hard to make contact with people	<input type="checkbox"/>	<input type="checkbox"/>
I'm in pain when I walk	<input type="checkbox"/>	<input type="checkbox"/>
The days seem to drag	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I have trouble getting up and down stairs or steps	<input type="checkbox"/>	<input type="checkbox"/>

REMEMBER IF YOU ARE NOT SURE WHETHER TO ANSWER YES OR NO TO A PROBLEM
TICK WHICHEVER ANSWER YOU THINK IS MORE TRUE AT THE MOMENT

	YES	NO
I find it hard to reach for things	<input type="checkbox"/>	<input type="checkbox"/>
I lose my temper easily these days	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I lie awake for most of the night	<input type="checkbox"/>	<input type="checkbox"/>
I feel as if I'm losing control	<input type="checkbox"/>	<input type="checkbox"/>
I'm in pain when I'm standing	<input type="checkbox"/>	<input type="checkbox"/>
	YES	NO
I feel there is nobody I am close to	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to dress myself	<input type="checkbox"/>	<input type="checkbox"/>

Please turn over

3.

CONFIDENTIAL INFORMATION

Survey no

--	--	--	--	--	--	--	--	--	--

YES NO

I soon run out of energy

☐☐

I find it hard to stand for long
(e.g. at the kitchen sink, waiting for a bus)

☐☐

I'm in constant pain

☐☐

YES NO

It takes me a long time to get to sleep

☐☐

I feel I am a burden to people

☐☐

YES NO

Worry is keeping me awake at night

☐☐

I feel that life is not worth living

☐☐

YES NO

I sleep badly at night

☐☐

I need help to walk about outside
(e.g. a walking aid or someone to support me)

☐☐

YES NO

I'm in pain when going up and down stairs or steps

☐☐

I wake up feeling depressed

☐☐

YES NO

I'm finding it hard to get on with people

☐☐

I'm in pain when I'm sitting

☐☐

Please turn over.

--	--	--	--	--	--	--

4.

CONFIDENTIAL INFORMATION

IN THE LIST BELOW, TICK YES FOR EACH ACTIVITY IN YOUR LIFE WHICH IS BEING AFFECTED BY YOUR STATE OF HEALTH.
TICK NO FOR EACH ACTIVITY WHICH IS NOT BEING AFFECTED, OR WHICH DOES NOT APPLY TO YOU

Is your present state of health causing problems with your

	YES	NO
Job of work (That is, paid employment)	<input type="checkbox"/>	<input type="checkbox"/>
Looking after the home (Examples: cleaning & cooking, repairs, odd jobs around the home etc)	<input type="checkbox"/>	<input type="checkbox"/>
Social Life (Examples: going out, seeing friends, going to the pub etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Home Life (That is: relationships with other people in your home)	<input type="checkbox"/>	<input type="checkbox"/>
Sex Life	<input type="checkbox"/>	<input type="checkbox"/>
Interests & Hobbies (Examples: sports, arts and crafts, do-it-yourself etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Holidays (Examples: summer or winter holidays, weekends away etc.)	<input type="checkbox"/>	<input type="checkbox"/>

NOW PLEASE GO BACK TO PAGE 1 AND MAKE SURE YOU HAVE ANSWERED YES OR NO TO EVERY QUESTION ON ALL PAGES OF THE QUESTIONNAIRE.

THANK YOU FOR YOUR HELP

Initials of fieldworker

Survey no

--	--	--	--	--	--	--

CONFIDENTIAL INFORMATION

Clients D.O.B
Date of interview

I would like to ask you some questions about how you manage with some everyday activities and tasks.

1. Firstly, some questions about how you get around inside the house. These questions apply to the last 2 days.

Have you used a wheelchair to get around **inside** the house

Y
N

If Y, Q 2. If N, Q 3.

2. Have you had another person helping you as well, say, for example to open doors or help you turn corners?

Y
N

Move on to Q 5.

3. Provided you have any walking aid you might normally use, have you been able to walk around the house without anyone beside you?

Y
N

If Y, Q 5. If N, Q 4.

4. Have you had more than one person at a time to help you walk around the house?

Y
N

MOBILITY SCORE - 0
write score in 1
box 2
3

--

5. Over the last couple of days, have you had help to get from your bed to a chair and back again?

Y
N

If Y, Q 6. If N, Q 8.

6. Has this help been ~~more~~ than just a little help from one person?

Y
N

If Y, Q 7. If N, Q 9.

7. Do you manage to keep your balance while sitting by yourself with your legs over the edge of the bed?

Y
N

Move on to Q 9.

Survey no

--	--	--	--	--	--	--	--	--	--

3. Have you had anyone beside you just in case?

Y
N

TRANSFER SCORE - 0
write score in
box

1
2
3

--

9. Again, over the last 2 days, have you gone up and down stairs at all?

Y
N

If Y, Q 10. If N, Q 11.

10. Have you done this without having anyone beside you?

Y
N

STAIRS SCORE - 0
write score in
box

1
2

--

11. Now I'd like to move onto some questions about your bladder and bowel function.

In the last week, have you been unable to make it to the toilet in time or to stop your self from passing water?

Y
N

If Y, Q 12. If N, Q 13.

12. Has there been any day in the last week when this has happened more than once?

Y
N

Move on to Q 13.

13. In the last week, have you used a catheter?

Y
N

If Y, Q 14. If N, Q 15.

14. Have you had help to manage this catheter in the last week?

Y
N

BLADDER SCORE - 0
write score in
box

1
2

--

15. In the last week, have you had any similar problems with your bowels?

Y
N

If Y, Q 16. If N, Q 17.

Survey No

--	--	--	--	--	--	--

16. Has this happened once only or more than once in the last week?

Once
More than once

Move on to Q 17.

17. Have you had an enema or a manual evacuation in the last week?

Y
N

BOWELS SCORE - 0
write score in 1
box 2

--

18. Over the last couple of days when you have used the toilet or commode, have you managed to get on and off, undress, and wipe yourself without any help from anyone at all?

Y
N

If Y, Q 20. If N, Q 19.

19. Have you managed any of this yourself?

Y
N

If Y, tick box next to each thing client has done him/her self.
If N, Q 20.

getting on and off
undressing
wiping

TOILET USE SCORE - 0
write score in 1
box 2

--

20. The next questions are about how you cope at meal times. Over the last couple of days have you eaten any food you like without it being mashed or blended first?

Y
N

If Y, Q 21. If N, Q 22

21. Once your food has been cooked and placed in front of you, have you, in the last 2 days, received help to cut it up or spread butter or margarine

Y
N

If Y, Q 22. If N, Q 23

22. Have you had help to feed yourself?

Y
N

FEEDING SCORE - 0
write score in 1
box 2

--

--	--	--	--	--	--	--	--	--	--

23. I'd like to go on to some questions about how you get dressed now.

Over the last couple of days have you managed to get your clothes out, put them on **and fasten** them without anyone else to help you?

Y
N

If Y, Q 25. If N, Q 24.

24. Have you put on any of your clothes without help even if you've needed help with fastening them?

Y
N

DRESSING SCORE - 0
write score in box 1
box 2

--

25. After someone has handed you the things you need, have you done the following tasks for yourself over the last 2 days?

Tick **No** when the client has not done the task (but only when someone else has done it for them or assisted them with it)

cleaned your teeth Y
N

fitted your false teeth (if you have any) Y
N

done your hair Y
N

washed your face Y
N

shaved yourself (men only) Y
N

GROOMING SCORE - 0
write score in box 1

--

Move on to Q 26.

26. Over the last week have you managed to get in and out of the bath or a shower **and wash yourself** without anyone else being with you at all

Y
N

BATHING SCORE - 0
write score in box 1

--

Was the carer present during the interview Y
N

Tick if **mainly** carer responses to questions

--

TOTAL SCORE
write score in box

--	--

APPENDIX 6

CLIENT-HELD DIARY SHEET

NEWCASTLE HEALTH COMMUNITY PHYSIOTHERAPY SANDERSON CENTRE

caring is our concern

NORTH AVENUE
GOSFORTH,
NEWCASTLE UPON TYNE
NE3 4EL.
Telephone: TYNESIDE (091) 285 2315

IMPORTANT INFORMATION

Please do not discard

Your Ref:

Our Ref:

SAINSBURY TRUST ADULT COMMUNITY PHYSIOTHERAPY PROJECT

NOTES FOR STUDY CLIENTS

Please read these notes carefully yourself and ask any people from Health or Social Services you come into contact with to read them also.

These sheets are to record your contacts with some services in the community and with some hospital based services.

There are two sections:

SECTION A Your contacts with people from the Health Authority and Social Services. These may include:

1. District Nursing Sister
2. Nursing Auxiliary (Bath Nurse)
3. Community Psychiatric Nurse (C.P.N)
4. Community Occupational Therapist from Social Services
5. Hospital based Occupational Therapist
6. Physiotherapists (Community or Hospital-based)
7. Speech Therapists (Community or Hospital based)
8. Chiropodist (Community or Hospital/Clinic based)
9. Social Workers
10. Health Visitors
11. Psychologists
12. Doctors

You need not keep a record of your contacts with home helps or care attendants from outside agencies. The fieldworker will find this out at the end of the study.

SECTION B Any time you spend in respite or holiday relief care.

Please remember it is normal for some people to have a lot of contacts with services, and for others to have hardly any at all.

It is important for the study that this information is kept up to date. Please either fill these sheets in yourself or ask the professionals concerned to do it.

Please contact Mrs P Dawson, the Research Co-Ordinator on the above number if you have any queries or problems with the sheets.

THANK YOU FOR YOUR CO-OPERATION

Survey Number

5	0	9	4	0	5	i
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[illegible]

C O N F I D E N T I A L I N F O R M A T I O N

NEWCASTLE HEALTH AUTHORITY

SAINSBURY TRUST ADULT COMMUNITY PHYSIOTHERAPY PROJECT

SANDERSON CENTRE, NORTH AVENUE, GOSFORTH, NEWCASTLE UPON TYNE NE3 4EL

SECTION B - Time spent in respite care or holiday relief care

PLEASE DO NOT WRITE
IN BOXES

Date of starting respite care - _____

8

Which Hospital or Residential Home? (please specify on line below)

14

Date of returning home _____

15

Date of starting respite care - _____

21

Which Hospital or Residential Home? (please specify on line below)

27

Date of returning home _____

28

Date of starting respite care - _____

34

Which Hospital or Residential Home? (please specify on line below)

40

Date of returning home _____

41

Date of starting respite care - _____

47

Which Hospital or Residential Home? (please specify on line below)

53

Date of returning home _____

54

Date of starting respite care - _____

60

Which Hospital or Residential Home? (Please specify on line below)

66

Date of returning home _____

67

APPENDIX 7

GP-HELD RECORD CARD

NEWCASTLE HEALTH AUTHORITY

[illegible]

Contacts with G.P.
continued

Date of contact

27 ☐ 28 ☐ 29 ☐ 30 ☐ 31 ☐ 32 ☐ 33 ☒ 34 ☐ 35 ☐ 36 ☐

Don't know ☐ Consultation ☐ 1st surgery ☐ 2nd surgery ☐

Survey Number

Your referrals to other agencies.
Please write in date and tick appropriate box use a new line for each referral.

Date

If other please specify

Consultant
D Nurse
S Worker
C.P.N.
H Visitor
Speech Therapist
O.T.
Orthoptist
Other

1 2 3 4 5 6 7 8 0

8

9

10

11

12

13

14

15

16

1 2

APPENDIX 8

TABLES SHOWING ANALYSIS OF SAMPLE CHARACTERISTICS

Table 8.1. Comparisons between the trial sample (n=222) and the post-trial sample (n=85) on selected baseline variables [table continues overleaf]

Baseline variable	Response/category	Trial sample	Post-trial sample	Statistical test and probability
Age (years)	Median (IQR)	<u>n=222</u> 73(19)	<u>n=85</u> 70(18)	Mann Whitney 2 tailed p= 0.43
Gender	Male	<u>n=222</u> 89(40%)	<u>n=85</u> 35(41%)	Chi-square p= 0.82 (1DF)
	Female	133(60%)	50(59%)	
Primary diagnosis	Neurology	<u>n=205</u> 77(38%)	<u>n=72</u> 20(28%)	Chi-square p= 0.02 (3DF) SIG
	Orthopaedic/ Rheumatology	65(32%)	23(32%)	
	Respiratory	50(24%)	16(22%)	
	Other	13(6%)	13(18%)	
Independence in ADL [0=dependent 20=independent]	Barthel Index Score	<u>n=222</u>	<u>n=85</u>	Mann Whitney 2 tailed p= 0.39
	Median (IQR)	15(8)	13(10)	
Health Status [100=poor health 0=good health]	Nottingham Health Profile Scores			Mann Whitney 2 tailed p= 0.93 0.57 0.90 0.24 0.86 0.86
	Energy Median (IQR)	<u>n=200</u> 60.8(76)	<u>n=66</u> 60.8(76)	
	Pain Median (IQR)	<u>n=198</u> 28.7(63)	<u>n=66</u> 40(64)	
	Emotions Median (IQR)	<u>n=198</u> 26.6(46)	<u>n=66</u> 22.1(41)	
	Sleep Median (IQR)	<u>n=198</u> 38.5(65)	<u>n=66</u> 50.7(57)	
	Social Median (IQR)	<u>n=198</u> 22(42)	<u>n=66</u> 20.1(42)	
	Physical Mobility Median (IQR)	<u>n=199</u> 54.6(37)	<u>n=66</u> 54.5(32)	
Communication problems	Yes	<u>n=222</u> 49(22%)	<u>n=85</u> 31(36.5%)	Chi-square p= 0.01 (1DF) SIG
	No	173(78%)	54(63.5%)	

Baseline variable	Response/category	Trial sample	Post-trial sample	Statistical test and probability
Lives alone	Yes	<u>n=222</u> 67(34.5%)	<u>n=85</u> 20(27%)	Chi-square p= 0.25 (1DF) [not included in chi-square test]
	No	127(65.5%)	54(73%)	
	[Res Care]	[28]	[11]	
Housing Tenure	Home owner	<u>n=206</u> 64(31%)	<u>n=83</u> 31(37%)	Chi-square p= 0.22 (2DF)
	Rented	106(51%)	33(40%)	
	Res Care/ Sheltered Accommodation	36(18%)	19(23%)	
Informal carer	Yes	<u>n=114</u> 88(45%)	<u>n=85</u> 37(50%)	Chi-square p= 0.53 (1DF) [not included in chi-square test]
	No	106(55%)	37(50%)	
	[Res Care]	[28]	[11]	
Allocation to Area Physio Team	Central	<u>n=222</u> 70(31%)	<u>n=85</u> 19(22%)	Chi-square p= 0.42 (3DF)
	East	46(21%)	20(24%)	
	North	57(26%)	24(28%)	
	West	49(22%)	22(26%)	

Table 8.2. Comparisons between the experimental group (n=114) and the control group (n=108) on selected baseline variables [table continues overleaf]

Baseline variable	Response/category	Experimental group	Control group	Statistical test and probability
Age (years)	Median (IQR)	<u>n=114</u> 73(23)	<u>n=108</u> 73(16)	Mann Whitney 2 tailed p= 0.96
Gender	Male	<u>n=114</u> 48(42%)	<u>n=108</u> 41(38%)	Chi-square p= 0.53 (1DF)
	Female	66(58%)	67(62%)	
Primary diagnosis	Neurology	<u>n=110</u> 39(35.5%)	<u>n=95</u> 38(40%)	Chi-square p= 0.71 (3DF)
	Orthopaedic/ Rheumatology	35(32%)	30(32%)	
	Respiratory	30(27%)	20(21%)	
	Other	6(5.5%)	7(7%)	
Independence in ADL [0=dependent 20=independent]	Barthel Index Score	<u>n=114</u>	<u>n=108</u>	Mann Whitney 2 tailed p= 0.16
	Median (IQR)	15.5(7)	15(9)	
Health Status [100=poor health 0=good health]	Nottingham Health Profile Scores			Mann Whitney 2 tailed p= (corrected for ties)
	Energy Median (IQR)	<u>n=106</u> 60.8(76)	<u>n=94</u> 60.8(76)	
	Pain Median (IQR)	<u>n=104</u> 27.4(54)	<u>n=94</u> 30.3(61)	
	Emotions Median (IQR)	<u>n=104</u> 27.2(46)	<u>n=94</u> 24.7(44)	
	Sleep Median (IQR)	<u>n=105</u> 49(65)	<u>n=93</u> 34.9(65)	
	Social Median (IQR)	<u>n=105</u> 22(42)	<u>n=93</u> 22(42)	
	Physical Mobility Median (IQR)	<u>n=105</u> 53.4(36)	<u>n=94</u> 56.6(39)	
Communication problems	Yes	<u>n=114</u> 26(23%)	<u>n=108</u> 23(21%)	Chi-square p= 0.79 (1DF)
	No	88(77%)	85(79%)	

Baseline variable	Response/category	Experimental group	Control group	Statistical test and probability
Lives alone	Yes	<u>n=114</u> 34(33%)	<u>n=108</u> 33(36%)	Chi-square p= 0.71 (1DF) [not included in chi-square test]
	No	68(67%)	59(64%)	
	[Res Care]	[12]	[16]	
Housing Tenure	Home owner	<u>n=108</u> 34(31%)	<u>n=98</u> 30(31%)	Chi-square p= 0.56 (2DF)
	Rented	58(54%)	48(49%)	
	Res Care/ Sheltered Accommodation	16(15%)	20(20%)	
Informal carer	Yes	<u>n=114</u> 48(47%)	<u>n=108</u> 40(44%)	Chi-square p= 0.62 (1DF) [not included in chi-square test]
	No	54(53%)	52(57%)	
	[Res Care]	[12]	[16]	
Allocation to Area Physio Team	Central	<u>n=114</u> 36(31%)	<u>n=108</u> 34(32%)	Chi-square p= 0.80 (3DF)
	East	22(19%)	24(22%)	
	North	28(25%)	29(27%)	
	West	28(25%)	21(19%)	

Table 8.3. Whole sample comparisons at the 2nd interview stage between clients lost or dropped out from the trial (n=27) and those who were interviewed (n=195) on selected baseline variables

Baseline variable	Interviewed at 2nd stage n=195	Lost/dropped out at 2nd stage n=27	Statistical test and probability
Age	Median = 73 yrs Percentiles (25-75) = 64-82	Median = 73 yrs Percentiles (25-75) = 60-83	Mann-Whitney 2 tailed p = 0.99
Gender	Male = 76 (39%) Female = 119 (61%)	Male = 12 (44%) Female = 15 (56%)	Chi-square p= 0.75 (1 DF)
Barthel score [0=dependent 20=independent]	Median = 16 Percentiles (25-75) = 11-18	Median = 11 Percentiles (25-75) = 4-16	Mann-Whitney 2 tailed p=0.004 SIG
NHP energy score [100=poor health 0=good health]	Median = 61 Percentiles (25-75) = 24-100	Median = 61 Percentiles (25-75) = 24-100	Mann-Whitney 2 tailed p=0.51
NHP pain score [100=poor health 0=good health]	Median = 28 Percentiles (25-75) = 6-60	Median = 30 Percentiles (25-75) = 6-70	Mann-Whitney 2 tailed p=0.67
NHP emotions score [100=poor health 0=good health]	Median = 29 Percentiles (25-75) = 7-51	Median = 35 Percentiles (25-75) = 10-60	Mann-Whitney 2 tailed p=0.17
NHP sleep score [100=poor health 0=good health]	Median = 38 Percentiles (25-75) = 13-78	Median = 35 Percentiles (25-75) = 13-78	Mann-Whitney 2 tailed p=0.96
NHP social score [100=poor health 0=good health]	Median = 0 Percentiles (25-75) = 0-42	Median = 23 Percentiles (25-75) = 22-57	Mann-Whitney 2 tailed p=0.001 SIG
NHP physical mobility score [100=poor health 0=good health]	Median = 53 Percentiles (25-75) = 31-68	Median = 58 Percentiles (25-75) = 46-69	Mann-Whitney 2 tailed p=0.12
Communication problem	Yes = 42 (22%) No = 153 (78%)	Yes = 7 (26%) No = 20 (74%)	Chi-square p= 0.82 1DF
Lives alone	Yes = 61 (35%) No = 113 (65%) [Res care = 21]	Yes = 7 (30%) No = 16 (70%) [Res care = 4]	Chi-square p= 0.73 1DF [Excluded from test]
Carer	Yes = 75 (43%) No = 99 (57%) [Res care = 21]	Yes = 15 (65%) No = 8 (35%) [Res care = 4]	Chi-square p= 0.08 1DF [Excluded from test]

Table 8.4. Whole sample comparisons at the 3rd interview stage between clients lost or dropped out from the trial (n=60) and those who were interviewed (n=162) on selected baseline variables

Baseline variable	Interviewed at 3rd stage n=162	Lost/dropped out at 3rd stage n=60	Statistical test and probability
Age	Median = 73 yrs Percentiles (25-75) = 64-81	Median = 77 yrs Percentiles (25-75) = 60-84	Mann-Whitney 2 tailed p = 0.40
Gender	Male = 60 (37%) Female = 102 (63%)	Male = 29 (48%) Female = 31 (52%)	Chi-square p= 0.13 (1 DF)
Barthel score [0=dependent 20=independent]	Median = 16 Percentiles (25-75) = 11-18	Median = 12.5 Percentiles (25-75) = 6-18	Mann-Whitney 2 tailed p=0.02 SIG
NHP energy score [100=poor health 0=good health]	Median = 61 Percentiles (25-75) = 24-100	Median = 61 Percentiles (25-75) = 24-100	Mann-Whitney 2 tailed p=0.52
NHP pain score [100=poor health 0=good health]	Median = 27 Percentiles (25-75) = 6-59	Median = 31 Percentiles (25-75) = 9-71	Mann-Whitney 2 tailed p=0.50
NHP emotions score [100=poor health 0=good health]	Median = 24 Percentiles (25-75) = 7-49	Median = 32 Percentiles (25-75) = 7-60	Mann-Whitney 2 tailed p=0.33
NHP sleep score [100=poor health 0=good health]	Median = 38 Percentiles (25-75) = 13-78	Median = 35 Percentiles (25-75) = 15-78	Mann-Whitney 2 tailed p=0.47
NHP social score [100=poor health 0=good health]	Median = 0 Percentiles (25-75) = 0-40	Median = 23 Percentiles (25-75) = 0-57	Mann-Whitney 2 tailed p=0.003 SIG
NHP physical mobility score [100=poor health 0=good health]	Median = 47 Percentiles (25-75) = 29-66	Median = 66 Percentiles (25-75) = 44-77	Mann-Whitney 2 tailed p=0.005 SIG
Communication problem	Yes = 34 (21%) No = 128 (79%)	Yes = 15 (25%) No = 45 (75%)	Chi-square p= 0.52 1DF
Lives alone	Yes = 46 (32%) No = 98 (68%) [Res care = 18]	Yes = 21 (40%) No = 32 (60%) [Res care = 7]	Chi-square p= 0.31 1DF [Excluded from test]
Carer	Yes = 64 (44%) No = 80 (56%) [Res care = 18]	Yes = 26 (49%) No = 27 (51%) [Res care = 7]	Chi-square p= 0.49 1DF [Excluded from test]

Table 8.5. Experimental group comparisons at the 2nd interview stage between clients lost or dropped out from the trial (n=11) and those who were interviewed (n=103) on selected baseline variables

Baseline variable	Interviewed at 2nd stage n=103	Lost/dropped out at 2nd stage n=11	Statistical test and probability
Age	Median = 73 yrs Percentiles (25-75) = 59-82	Median = 76 yrs Percentiles (25-75) = 55-85	Mann-Whitney 2 tailed p = 0.76
Gender	Male = 44 (43%) Female = 59 (57%)	Male = 4 (36%) Female = 7 (64%)	Fisher's exact 2 tailed p= 0.76
Barthel score [0=dependent 20=independent]	Median = 16 Percentiles (25-75) = 12-18	Median = 12 Percentiles (25-75) = 6-16	Mann-Whitney 2 tailed p=0.07
NHP energy score [100=poor health 0=good health]	Median = 61 Percentiles (25-75) = 24-100	Median = 82 Percentiles (25-75) = 61-100	Mann-Whitney 2 tailed p=0.22
NHP pain score [100=poor health 0=good health]	Median = 26 Percentiles (25-75) = 1-59	Median = 38 Percentiles (25-75) = 7-77	Mann-Whitney 2 tailed p=0.51
NHP emotions score [100=poor health 0=good health]	Median = 27 Percentiles (25-75) = 7-56	Median = 26 Percentiles (25-75) = 9-43	Mann-Whitney 2 tailed p=0.33
NHP sleep score [100=poor health 0=good health]	Median = 50 Percentiles (25-75) = 13-78	Median = 35 Percentiles (25-75) = 17-92	Mann-Whitney 2 tailed p=0.47
NHP social score [100=poor health 0=good health]	Median = 19 Percentiles (25-75) = 0-42	Median = 32 Percentiles (25-75) = 21-64	Mann-Whitney 2 tailed p=0.006 SIG
NHP physical mobility score [100=poor health 0=good health]	Median = 51 Percentiles (25-75) = 31-68	Median = 58 Percentiles (25-75) = 46-69	Mann-Whitney 2 tailed p=0.34
Communication problem	Yes = 23 (22%) No = 80 (78%)	Yes = 3 (27%) No = 8 (73%)	Fisher's exact 2 tailed p= 0.71
Lives alone	Yes = 33 (35.5%) No = 60 (64.5%) [Res care = 10]	Yes = 1 (11%) No = 8 (89%) [Res care = 2]	Fisher's exact 2 tailed p= 0.27 [Excluded from test]
Carer	Yes = 42 (45%) No = 51 (55%) [Res care = 10]	Yes = 6 (67%) No = 3 (33%) [Res care = 2]	Fisher's exact 2 tailed p= 0.30 [Excluded from test]

Table 8.6. Experimental group comparisons at the 3rd interview stage between clients lost or dropped out from the trial (n=27) and those who were interviewed (n=87) on selected baseline variables

Baseline variable	Interviewed at 3rd stage n=87	Lost/dropped out at 3rd stage n=27	Statistical test and probability
Age	Median = 73 yrs Percentiles (25-75) = 62-82	Median = 76 yrs Percentiles (25-75) = 56-85	Mann-Whitney 2 tailed p = 0.82
Gender	Male = 35 (40%) Female = 52 (60%)	Male = 13 (48%) Female = 14 (52%)	Chi-square p= 0.47 (1 DF)
Barthel score [0=dependent 20=independent]	Median = 16 Percentiles (25-75) = 13-18	Median = 14 Percentiles (25-75) = 7-18	Mann-Whitney 2 tailed p=0.18
NHP energy score [100=poor health 0=good health]	Median = 61 Percentiles (25-75) = 24-100	Median = 63 Percentiles (25-75) = 37-100	Mann-Whitney 2 tailed p=0.52
NHP pain score [100=poor health 0=good health]	Median = 26 Percentiles (25-75) = 0-50	Median = 29 Percentiles (25-75) = 7-69	Mann-Whitney 2 tailed p=0.66
NHP emotions score [100=poor health 0=good health]	Median = 26 Percentiles (25-75) = 7-48	Median = 34 Percentiles (25-75) = 7-70	Mann-Whitney 2 tailed p=0.45
NHP sleep score [100=poor health 0=good health]	Median = 38 Percentiles (25-75) = 13-73	Median = 65 Percentiles (25-75) = 26-78	Mann-Whitney 2 tailed p=0.03 SIG
NHP social score [100=poor health 0=good health]	Median = 19 Percentiles (25-75) = 0-23	Median = 31 Percentiles (25-75) = 0-56	Mann-Whitney 2 tailed p=0.02 SIG
NHP physical mobility score [100=poor health 0=good health]	Median = 47 Percentiles (25-75) = 31-66	Median = 57 Percentiles (25-75) = 35-72	Mann-Whitney 2 tailed p=0.14
Communication problem	Yes = 20 (23%) No = 67 (77%)	Yes = 6 (22%) No = 21 (78%)	Chi-square p= 0.93 1DF
Lives alone	Yes = 24 (30%) No = 55 (70%) [Res care = 8]	Yes = 10 (43.5%) No = 13 (56.5%) [Res care = 4]	Chi-square p= 0.24 1DF [Excluded from test]
Carer	Yes = 38 (48%) No = 41 (52%) [Res care = 8]	Yes = 10 (43.5%) No = 13 (56.5%) [Res care = 4]	Chi-square p= 0.70 1DF [Excluded from test]

Table 8.7. Control group comparisons at the 2nd interview stage between clients lost or dropped out from the trial (n=16) and those who were interviewed (n=92) on selected baseline variables

Baseline variable	Interviewed at 2nd stage n=92	Lost/dropped out at 2nd stage n=16	Statistical test and probability
Age	Median = 73 yrs Percentiles (25-75) = 64-80	Median = 71 yrs Percentiles (25-75) = 59-81	Mann-Whitney 2 tailed p = 0.84
Gender	Male = 33 (36%) Female = 59 (64%)	Male = 8 (50%) Female = 8 (50%)	Chi-square p= 0.43 (1 DF)
Barthel score [0=dependent 20=independent]	Median = 16 Percentiles (25-75) = 10-18	Median = 8.5 Percentiles (25-75) = 2.5-16.5	Mann-Whitney 2 tailed p=0.03 SIG
NHP energy score [100=poor health 0=good health]	Median = 61 Percentiles (25-75) = 24-100	Median = 61 Percentiles (25-75) = 24-100	Mann-Whitney 2 tailed p=0.96
NHP pain score [100=poor health 0=good health]	Median = 31 Percentiles (25-75) = 10-72	Median = 30 Percentiles (25-75) = 6-70	Mann-Whitney 2 tailed p=0.87
NHP emotions score [100=poor health 0=good health]	Median = 17 Percentiles (25-75) = 0-50	Median = 41 Percentiles (25-75) = 10-66	Mann-Whitney 2 tailed p=0.08
NHP sleep score [100=poor health 0=good health]	Median = 36 Percentiles (25-75) = 13-78	Median = 34 Percentiles (25-75) = 13-73	Mann-Whitney 2 tailed p=0.56
NHP social score [100=poor health 0=good health]	Median = 0 Percentiles (25-75) = 0-41	Median = 23 Percentiles (25-75) = 22-45	Mann-Whitney 2 tailed p=0.02 SIG
NHP physical mobility score [100=poor health 0=good health]	Median = 55 Percentiles (25-75) = 23-68	Median = 57 Percentiles (25-75) = 46-78	Mann-Whitney 2 tailed p=0.27
Communication problem	Yes = 19 (21%) No = 73 (79%)	Yes = 4 (25%) No = 12 (75%)	Fisher's exact 2 tailed p= 0.74
Lives alone	Yes = 28 (35%) No = 53 (65%) [Res care = 11]	Yes = 6 (43%) No = 8 (57%) [Res care = 2]	Chi-square p= 0.77 1DF [Excluded from test]
Carer	Yes = 33 (41%) No = 48 (59%) [Res care = 11]	Yes = 9 (64%) No = 5 (36%) [Res care = 2]	Chi-square p= 0.19 1DF [Excluded from test]

Table 8.8. Control group comparisons at the 3rd interview stage between clients lost or dropped out from the trial (n=33) and those who were interviewed (n=75) on selected baseline variables

Baseline variable	Interviewed at 3rd stage n=75	Lost/dropped out at 3rd stage n=33	Statistical test and probability
Age	Median = 73 yrs Percentiles (25-75) = 64-79	Median = 77 yrs Percentiles (25-75) = 64-84	Mann-Whitney 2 tailed p = 0.33
Gender	Male = 25 (33%) Female = 50 (67%)	Male = 16 (48.5%) Female = 17 (51.5%)	Chi-square p= 0.14 (1 DF)
Barthel score [0=dependent 20=independent]	Median = 16 Percentiles (25-75) = 10-18	Median = 12 Percentiles (25-75) = 5-18	Mann-Whitney 2 tailed p=0.09
NHP energy score [100=poor health 0=good health]	Median = 61 Percentiles (25-75) = 24-100	Median = 61 Percentiles (25-75) = 24-100	Mann-Whitney 2 tailed p=0.70
NHP pain score [100=poor health 0=good health]	Median = 27 Percentiles (25-75) = 10-69	Median = 32 Percentiles (25-75) = 10-72	Mann-Whitney 2 tailed p=0.61
NHP emotions score [100=poor health 0=good health]	Median = 20 Percentiles (25-75) = 0-50	Median = 29 Percentiles (25-75) = 7-60	Mann-Whitney 2 tailed p=0.57
NHP sleep score [100=poor health 0=good health]	Median = 50 Percentiles (25-75) = 13-78	Median = 34 Percentiles (25-75) = 13-73	Mann-Whitney 2 tailed p=0.28
NHP social score [100=poor health 0=good health]	Median = 0 Percentiles (25-75) = 0-41	Median = 23 Percentiles (25-75) = 0-58	Mann-Whitney 2 tailed p=0.05 SIG
NHP physical mobility score [100=poor health 0=good health]	Median = 48 Percentiles (25-75) = 22-67	Median = 67 Percentiles (25-75) = 47-78	Mann-Whitney 2 tailed p=0.02 SIG
Communication problem	Yes = 14 (19%) No = 61 (81%)	Yes = 9 (27%) No = 24 (73%)	Chi-square p= 0.31 1DF
Lives alone	Yes = 22 (34%) No = 43 (66%) [Res care = 10]	Yes = 11 (37%) No = 19 (63%) [Res care = 3]	Chi-square p= 0.79 1DF [Excluded from test]
Carer	Yes = 26 (40%) No = 39 (60%) [Res care = 10]	Yes = 17 (56%) No = 13 (44%) [Res care = 3]	Chi-square p= 0.17 1DF [Excluded from test]

Table 8.9. Comparisons on selected baseline variables between the experimental group (n=87) and the control group (n=75) remaining in the trial at the 3rd interview stage [table continues overleaf]

Baseline variable	Response/category	Experimental group n=87	Control group n=75	Statistical test and probability
Age (years)	Median (IQR)	<u>n=87</u> 73(20)	<u>n=75</u> 73(15)	Mann Whitney 2 tailed p= 0.82
Gender	Male	<u>n=87</u> 35(40%)	<u>n=75</u> 25(33%)	Chi-square p= 0.36 (1DF)
	Female	52(60%)	50(67%)	
Primary diagnosis	Neurology	<u>n=85</u> 32(38%)	<u>n=70</u> 28(40%)	Chi-square p= 0.94 (3DF) [2 cells with expected frequency <5]
	Orthopaedic/ Rheumatology	29(34%)	23(33%)	
	Respiratory	20(23%)	17(24%)	
	Other	4(5%)	2(3%)	
Independence in ADL [0=dependent 20=independent]	Barthel Index Score	<u>n=87</u>	<u>n=75</u>	Mann Whitney 2 tailed p= 0.42
	Median (IQR)	16(5)	16(8)	
Health Status [100=poor health 0=good health]	Nottingham Health Profile Scores			Mann Whitney 2 tailed p=
	Energy Median (IQR)	<u>n=73</u> 60.8(76)	<u>n=61</u> 60.8(76)	
	Pain Median (IQR)	<u>n=70</u> 26(50)	<u>n=60</u> 27(59)	
	Emotions Median (IQR)	<u>n=68</u> 26.2(41)	<u>n=60</u> 29.8(49)	
	Sleep Median (IQR)	<u>n=71</u> 38.5(60)	<u>n=59</u> 50.4(65)	
	Social Median (IQR)	<u>n=69</u> 19.4(23)	<u>n=59</u> 0(41)	
	Physical Mobility Median (IQR)	<u>n=70</u> 47.3(35)	<u>n=60</u> 47.6(44)	
Communication problems	Yes	<u>n=87</u> 20(23%)	<u>n=75</u> 14(19%)	Chi-square p= 0.50 (1DF)
	No	67(77%)	61(81%)	

Baseline variable	Response/category	Experimental group n=87	Control group n=75	Statistical test and probability
Lives alone	Yes	<u>n=79</u> 24(30%)	<u>n=65</u> 22(34%)	Chi-square p= 0.66 (1DF)
	No	55(70%)	43(66%)	
	[Res Care]	[8]	[11]	[not included in chi-square test]
Housing Tenure	Home owner	<u>n=86</u> 28(33%)	<u>n=74</u> 25(34%)	Chi-square p= 0.26 (2DF)
	Rented	48(56%)	34(46%)	
	Res Care/ Sheltered Accommodation	10(11%)	15(20%)	
Informal carer	Yes	<u>n=87</u> 38(48%)	<u>n=75</u> 26(40%)	Chi-square p= 0.33 (1DF)
	No	41(52%)	39(60%)	
	[Res Care]	[8]	[10]	[not included in chi-square test]
Allocation to Area Physio Team	Central	<u>n=87</u> 26(30%)	<u>n=75</u> 27(36%)	Chi-square p= 0.62 (3DF)
	East	15(17%)	15(20%)	
	North	27(31%)	22(29%)	
	West	19(22%)	11(15%)	

APPENDIX 9

TABLES SHOWING ANALYSIS OF INDIVIDUAL ITEMS OF THE BARTHEL INDEX

MOBILITY

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (immobile)	12 (14%)	15 (20%)	9 (10%)	11 (15%)	12 (14%)	13 (17%)
1 (wheelchair independent)	3 (3%)	7 (9%)	5 (6%)	7 (9%)	3 (3%)	8 (11%)
2 (walks with one)	11 (13%)	8 (11%)	4 (5%)	5 (7%)	5 (6%)	4 (5%)
3 (independently mobile)	61 (70%)	45 (60%)	69 (79%)	52 (69%)	67 (77%)	50 (67%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=3.9
p=0.27

chi-square=2.2
p=0.54

chi-square=4.0
p=0.26
(25% cells with
expected
frequency <5)

TRANSFERS

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (unable to transfer)	4 (4.5%)	9 (12%)	3 (3.5%)	5 (7%)	6 (7%)	9 (12%)
1 (needs major help with transfers)	11 (12.5%)	9 (12%)	9 (10%)	8 (11%)	5 (6%)	6 (8%)
2 (needs minor help with transfers)	21 (24%)	10 (13%)	19 (22%)	14 (19%)	27 (31%)	16 (21%)
3 (independent in transfers)	51 (59%)	47 (63%)	56 (64.5%)	48 (64%)	49 (56%)	44 (59%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=5.3
p=0.15

chi-square=1.1
p=0.79
(25% cells with
expected
frequency <5)

chi-square=2.9
p=0.41

STAIRS

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (unable to climb stairs)	49 (56.3%)	49 (65%)	41 (47%)	43 (57%)	49 (56%)	48 (64%)
1 (needs help on stairs)	9 (10.3%)	6 (8%)	2 (2%)	6 (8%)	4 (5%)	3 (4%)
2 (independent on stairs)	29 (33.3%)	20 (27%)	44 (51%)	26 (35%)	34 (39%)	24 (32%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=1.4
p=0.50

chi-square=5.8
p=0.05
(33% cells with
expected
frequency <5)

chi-square=0.99
p=0.61
(33% cells with
expected
frequency <5)

STAIRS (COLLAPSED CATEGORIES)

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
unable to climb stairs or needs help	58 (67%)	55 (73%)	43 (49%)	49 (65%)	53 (61%)	51 (68%)
Independent on stairs	29 (33%)	20 (27%)	44 (51%)	26 (35%)	34 (39%)	24 (32%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=0.85
p=0.39

chi-square=4.15
p=0.056

chi-square=0.88
p=0.41

BLADDER

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (incontinent)	9 (10.3%)	14 (19%)	10 (12%)	10 (13%)	11 (13%)	14 (19%)
1 (occasional accident)	9 (10.3%)	8 (11%)	9 (10%)	6 (8%)	4 (4%)	3 (4%)
2 (continent)	69 (79.3%)	53 (71%)	68 (78%)	59 (79%)	72 (83%)	58 (77%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=2.4
p=0.31

chi-square=0.4
p=0.84

chi-square=1.1
p=0.57
(33% cells with
expected
frequency <5)

BOWELS

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (incontinent)	1 (1%)	4 (5.3%)	4 (5%)	4 (5%)	4 (5%)	5 (7%)
1 (occasional accident)	2 (2%)	1 (1.3%)	1 (1%)	3 (4%)	2 (2%)	3 (4%)
2 (continent)	84 (97%)	70 (93.3%)	82 (94%)	68 (91%)	81 (93%)	67 (89%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=2.5
p=0.06
(67% cells with
expected
frequency <5)

chi-square=1.4
p=0.49
(67% cells with
expected
frequency <5)

chi-square=0.8
p=0.69
(67% cells with
expected
frequency <5)

TOILET USE

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (unable to toilet independently)	11 (13%)	13 (17.3%)	12 (14%)	10 (13.3%)	13 (15%)	13 (17%)
1 (needs help to toilet)	3 (3%)	7 (9.3%)	2 (2%)	7 (9.3%)	0 (0%)	6 (8%)
2 (independent in toilet use)	73 (84%)	55 (73.3%)	73 (84%)	58 (77.3%)	74 (85%)	56 (75%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=3.4
p=0.18
(17% cells with
expected
frequency <5)

chi-square=3.8
p=0.14
(33% cells with
expected
frequency <5)

chi-square=7.6
p=0.02
(33% cells with
expected
frequency <5)

FEEDING

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (unable to feed independently)	6 (7%)	10 (13.3%)	5 (6%)	7 (9.3%)	3 (3%)	8 (11%)
1 (needs help to feed)	26 (30%)	19 (25.3%)	19 (22%)	19 (25.3%)	25 (29%)	22 (29%)
2 (independent in feeding)	55 (63%)	46 (61.3%)	63 (72%)	49 (65.3%)	59 (68%)	45 (60%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=2.0
p=0.37

chi-square=1.2
p=0.55

chi-square=3.5
p=0.18

DRESSING

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (unable to dress independently)	22 (25%)	17 (23%)	13 (15%)	16 (21.3%)	19 (22%)	16 (21%)
1 (needs help to dress)	18 (21%)	19 (25%)	17 (19.5%)	13 (17.3%)	17 (19%)	16 (21%)
2 (independent in dressing)	47 (54%)	39 (52%)	57 (65.5%)	46 (61.3%)	51 (59%)	43 (58%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=0.5
p=0.77

chi-square=1.1
p=0.57

chi-square=0.08
p=0.96

GROOMING

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (needs help to groom)	16 (18%)	17 (23%)	13 (15%)	16 (21%)	17 (19.5%)	15 (20%)
1 (independent in grooming)	71 (82%)	58 (77%)	74 (85%)	59 (79%)	70 (80.5%)	60 (80%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=0.5
p=0.50

chi-square=1.1
p=0.29

chi-square=0.0
p=0.94

BATHING

BI score	on referral		3 months		12 months	
	expt	control	expt	control	expt	control
0 (dependent in bathing)	59 (68%)	55 (73%)	54 (62%)	54 (72%)	56 (64%)	53 (71%)
1 (independent in bathing)	28 (32%)	20 (27%)	33 (38%)	21 (28%)	31 (36%)	22 (29%)
total	87 (100%)	75 (100%)	87 (100%)	75 (100%)	87 (100%)	75 (100%)

chi-square=0.6
p=0.44

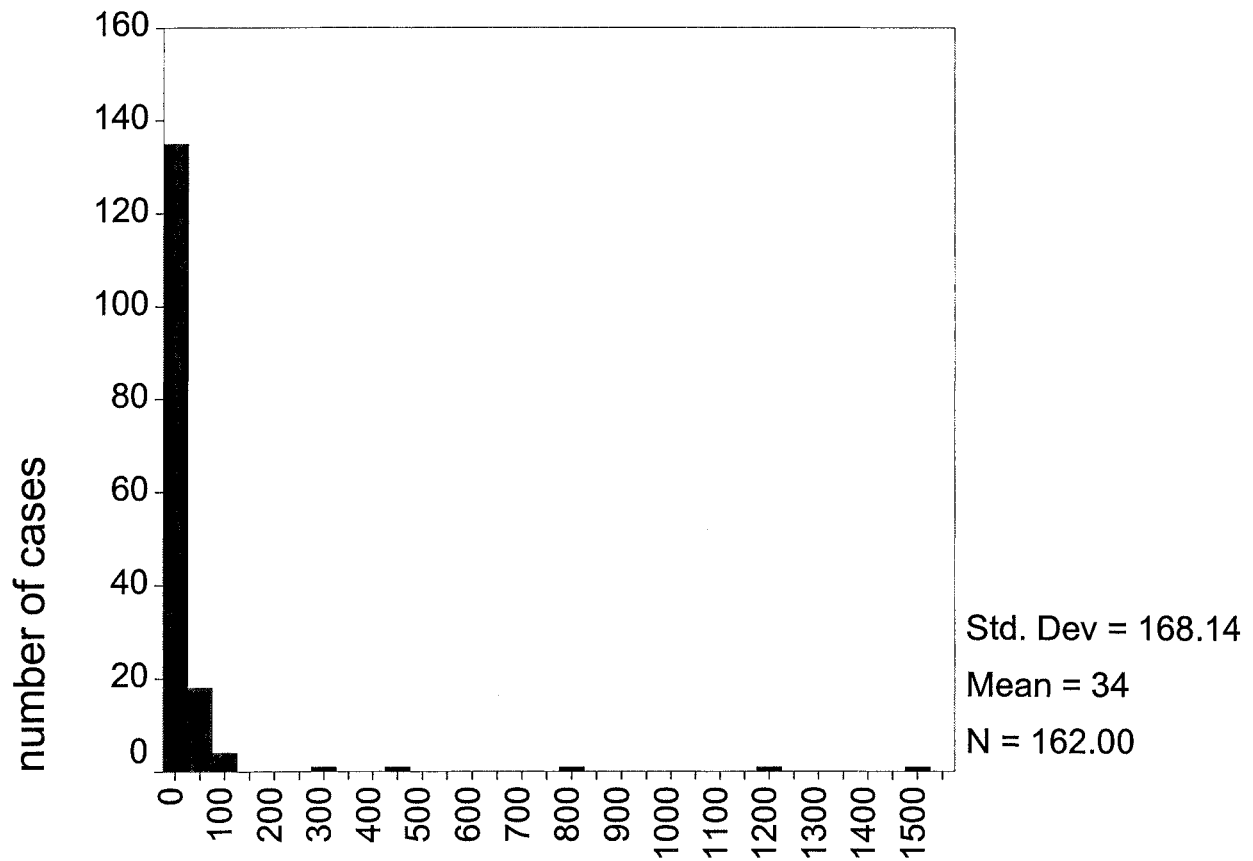
chi-square=1.8
p=0.18

chi-square=0.9
p=0.36

APPENDIX 10

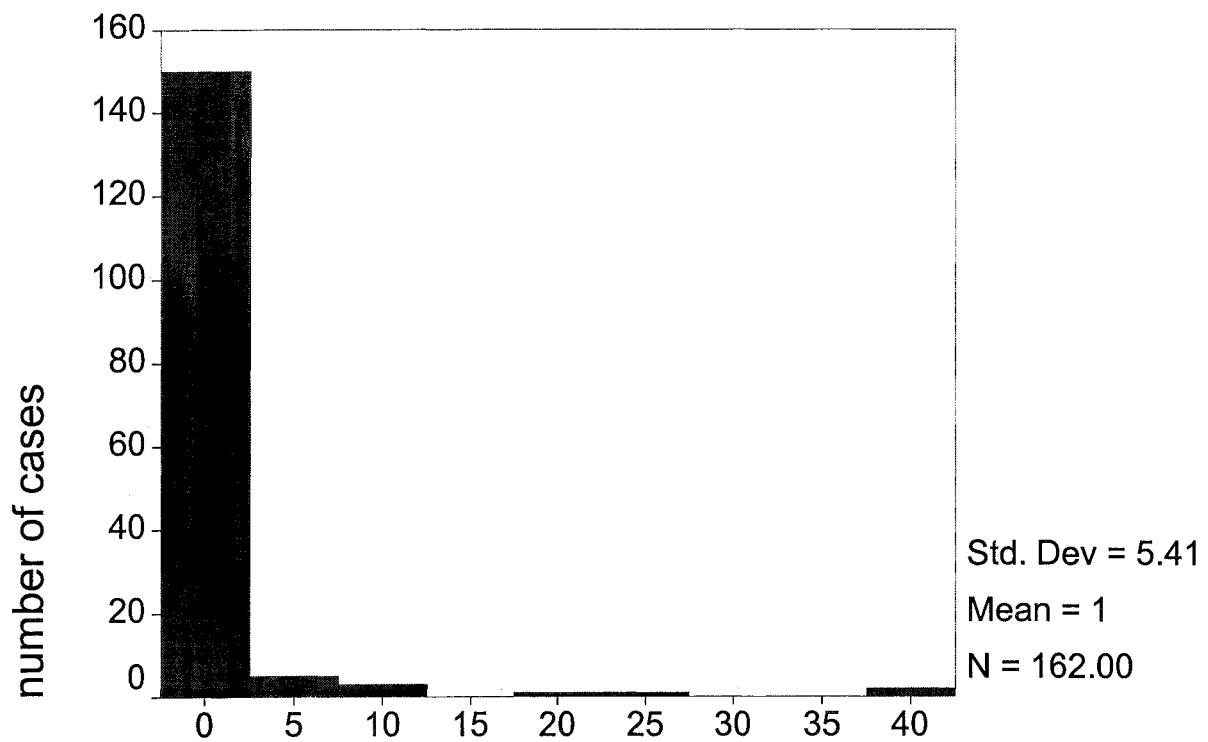
HISTOGRAMS OF CONTACTS WITH HEALTH AND SOCIAL SERVICES

Histogram of contacts with auxiliary nurses



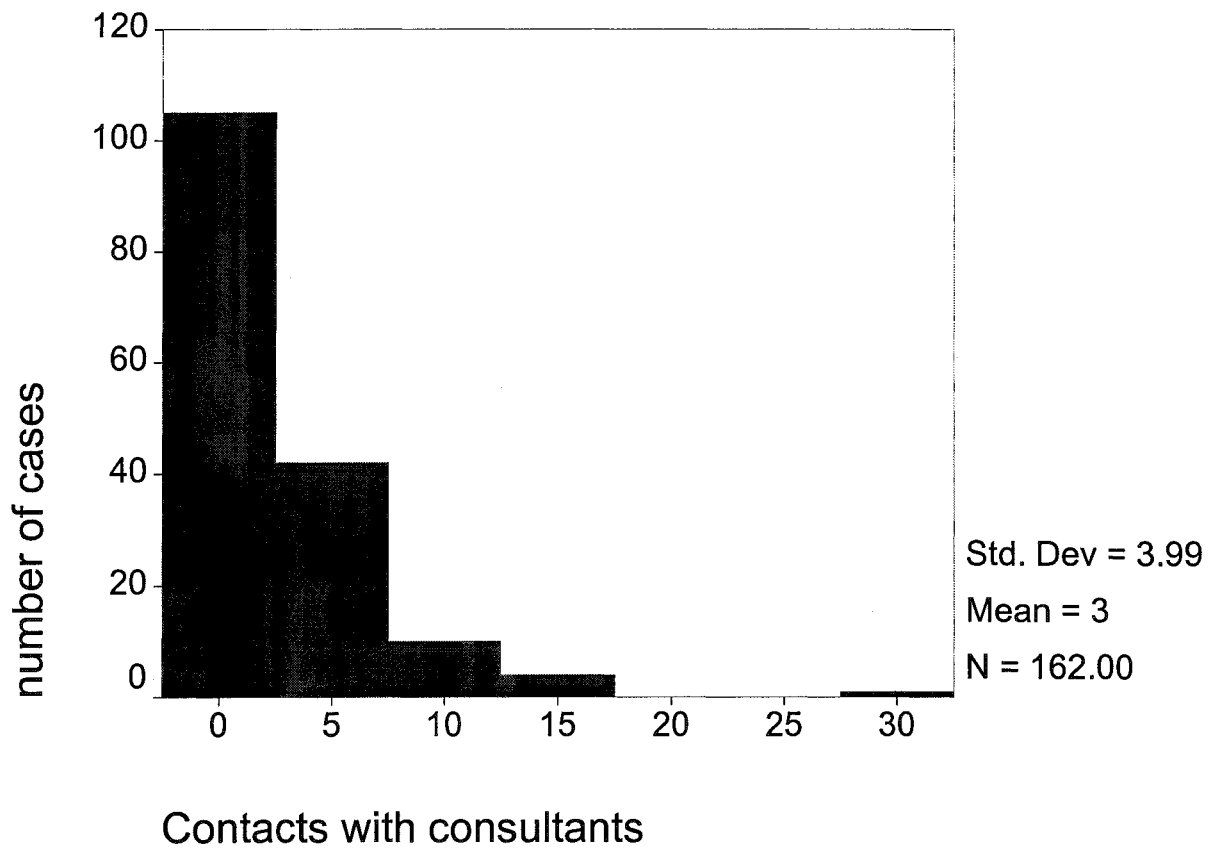
Contacts with auxiliary nurses

Histogram of contacts with out-patient physiotherapists

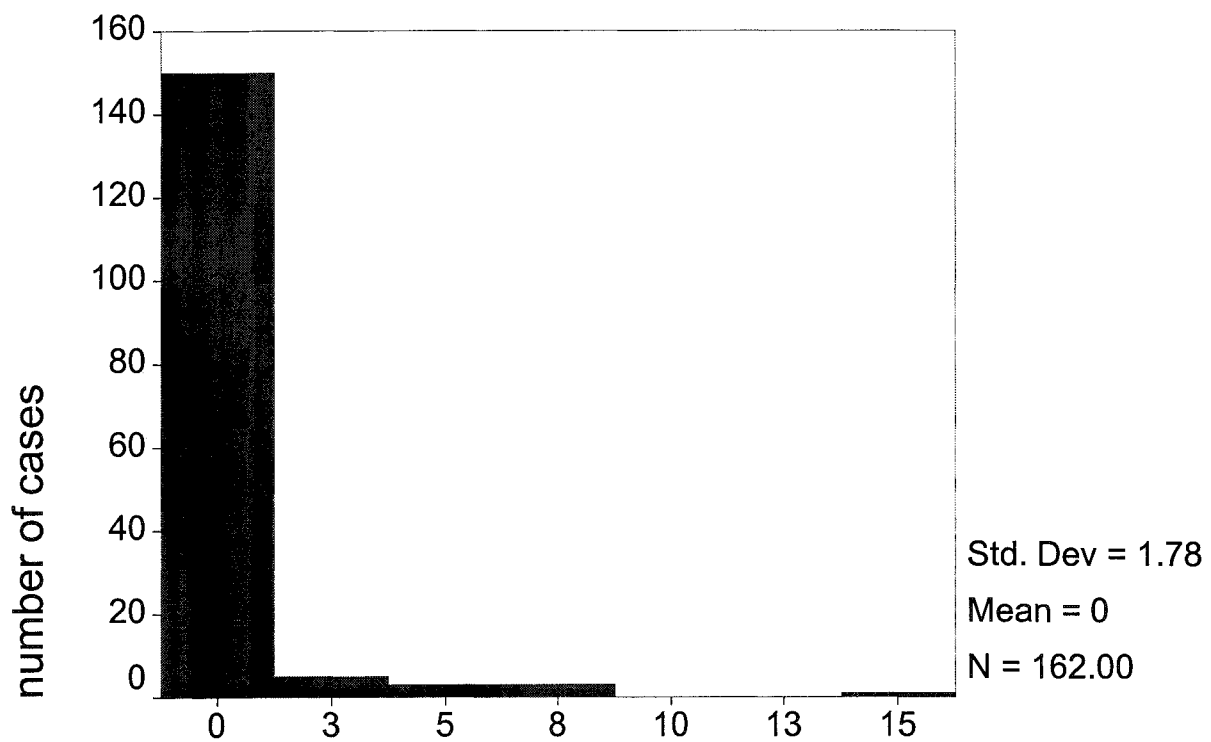


Contacts with out patient physiotherapists

Histogram of contacts with consultants

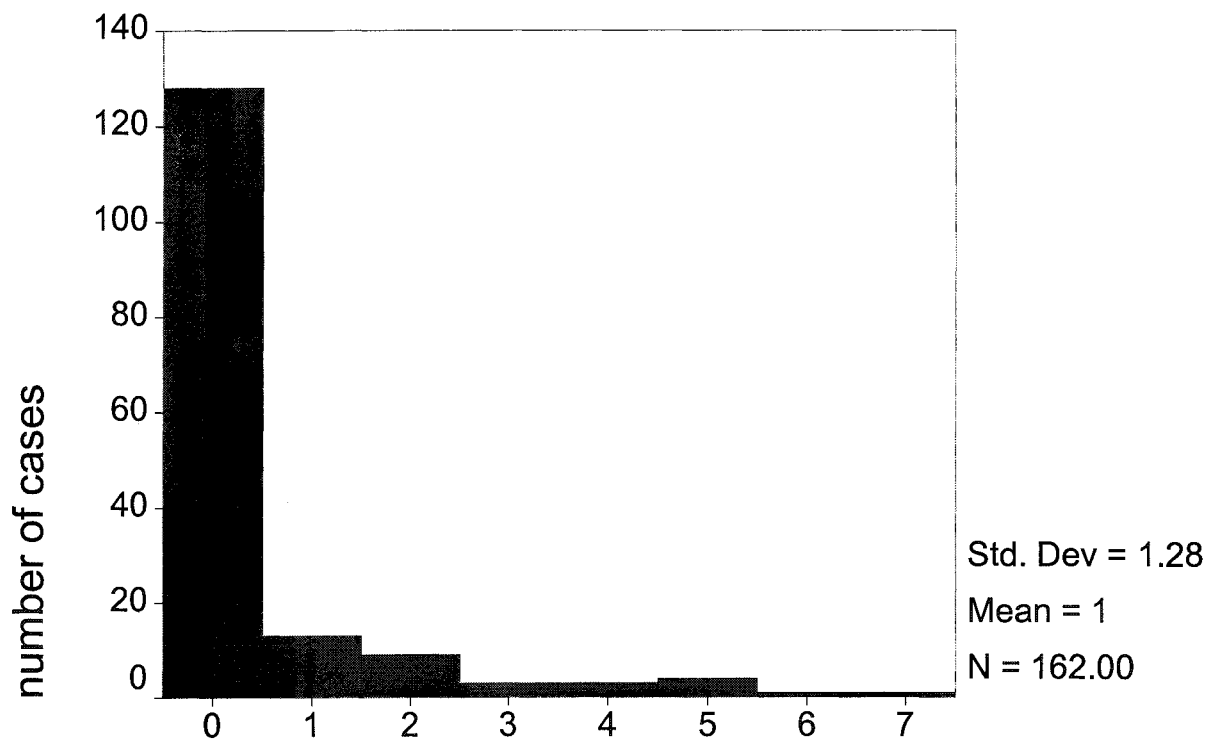


Histogram of contacts with social services occupational therapists



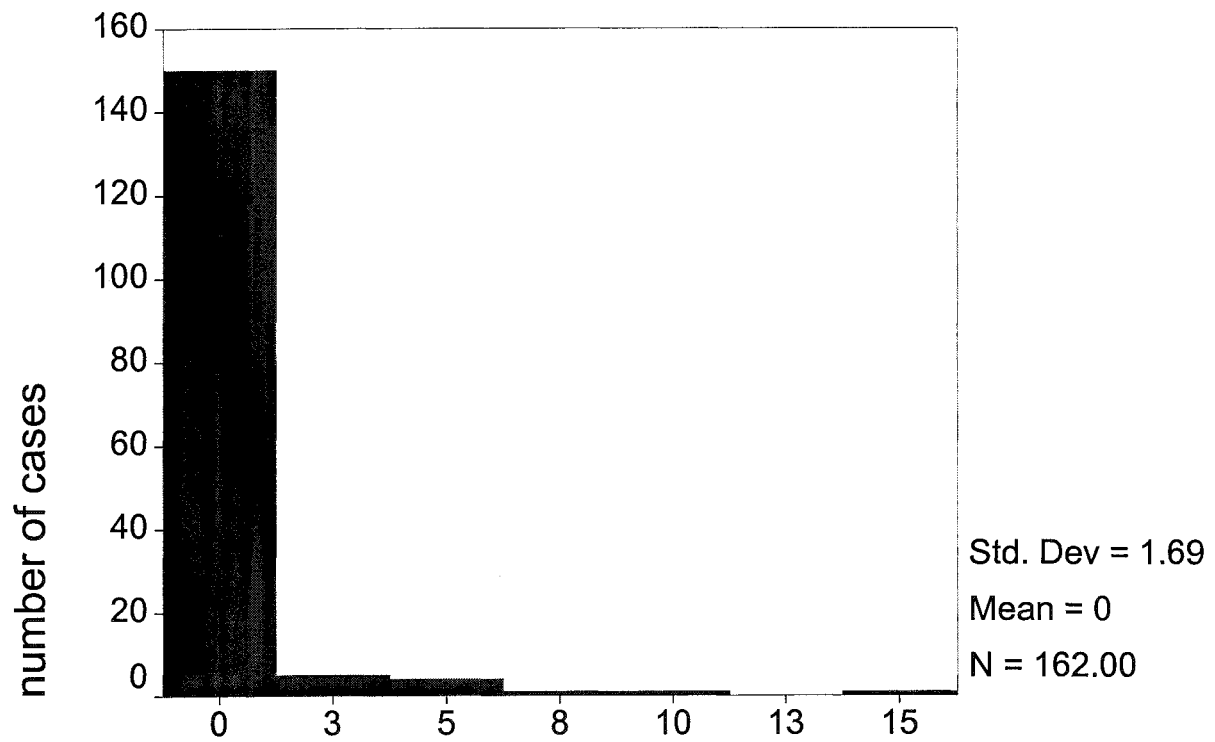
Contacts with social services occupational therapists

Histogram of contacts with social workers



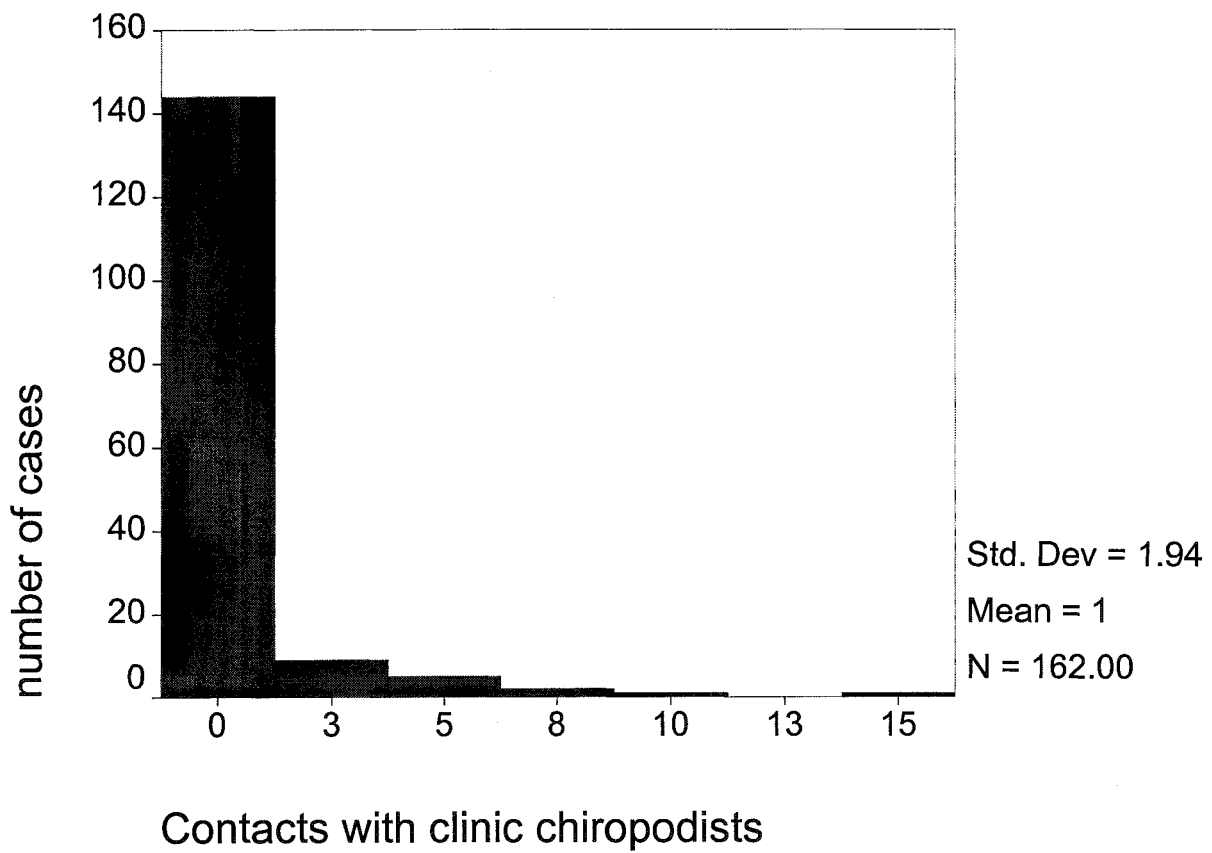
Contacts with social workers

Histogram of contacts with domiciliary chiropodists

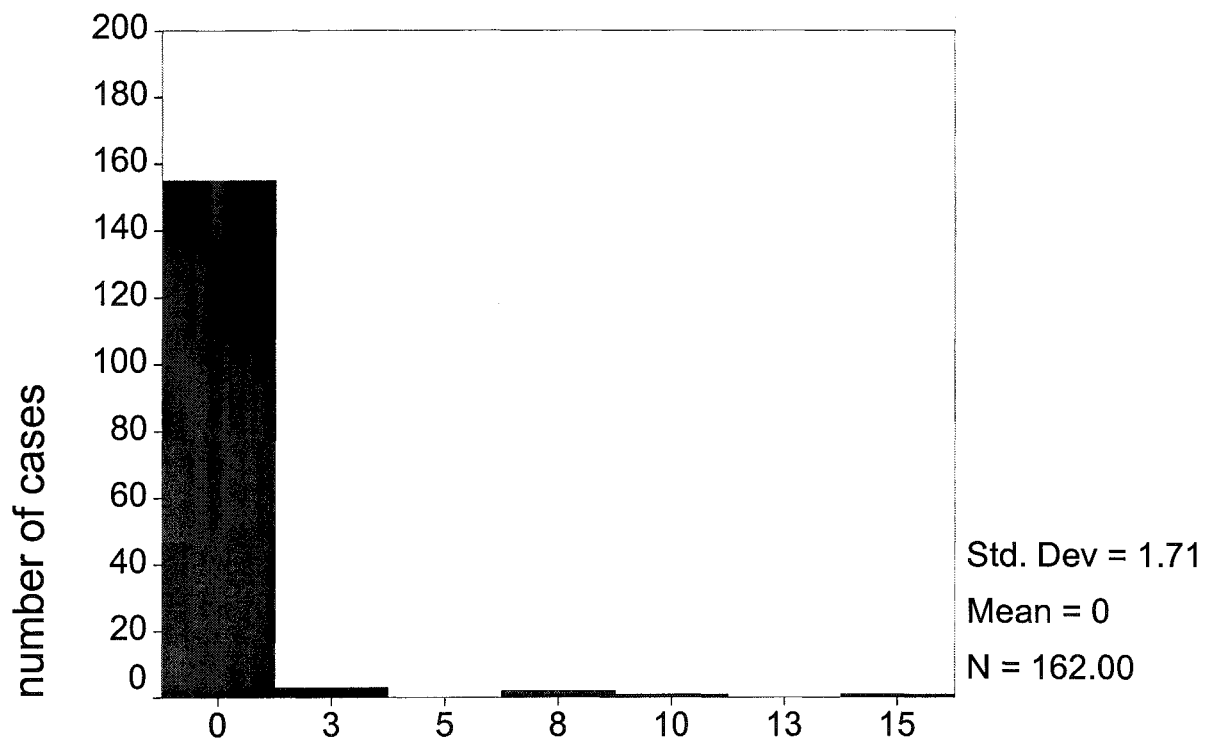


Contacts with domiciliary chiropodists

Histogram of contacts with clinic chiropodists

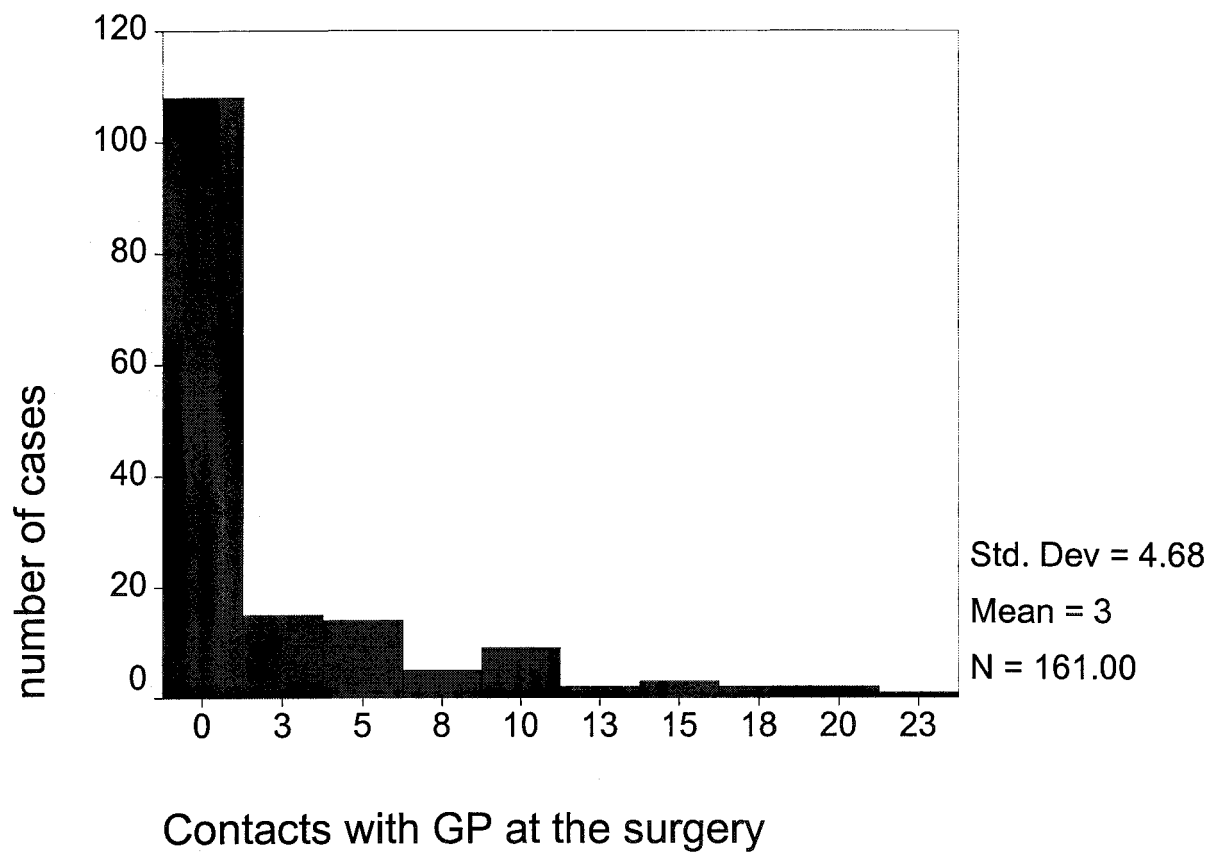


Histogram of contacts with domiciliary speech therapists

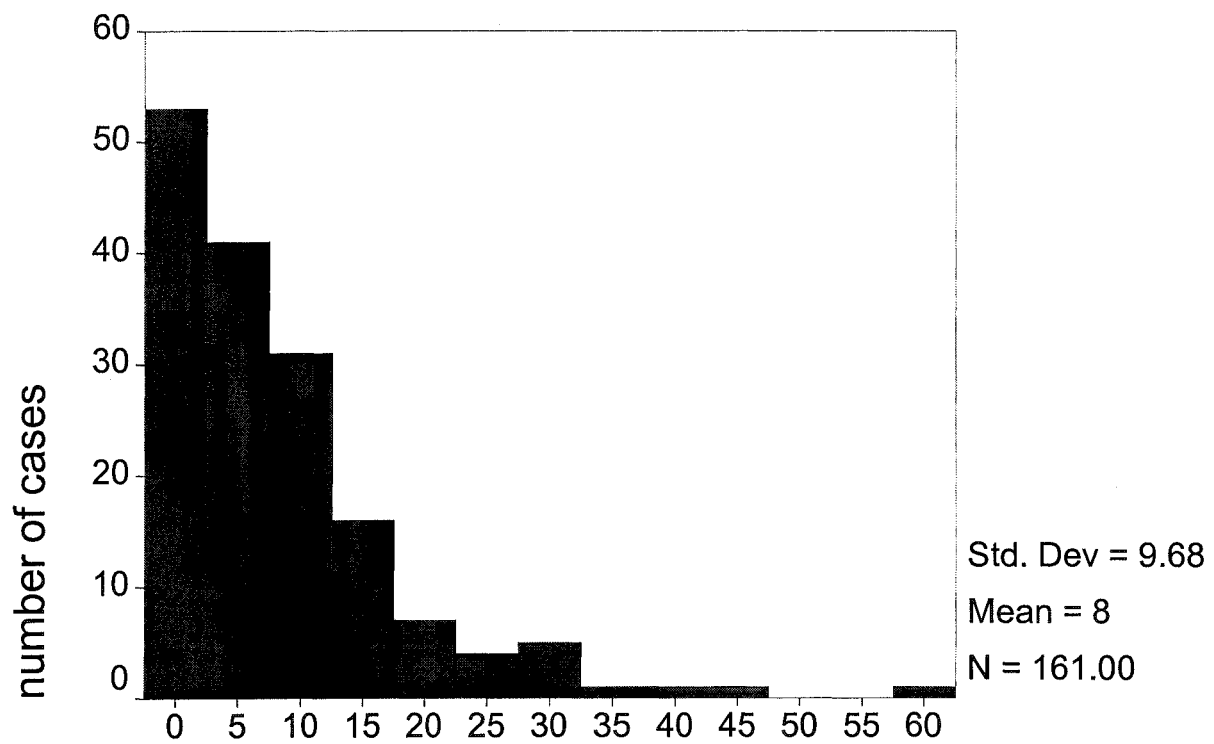


Contacts with domiciliary speech therapists

Histogram of contacts with GPs in the surgery

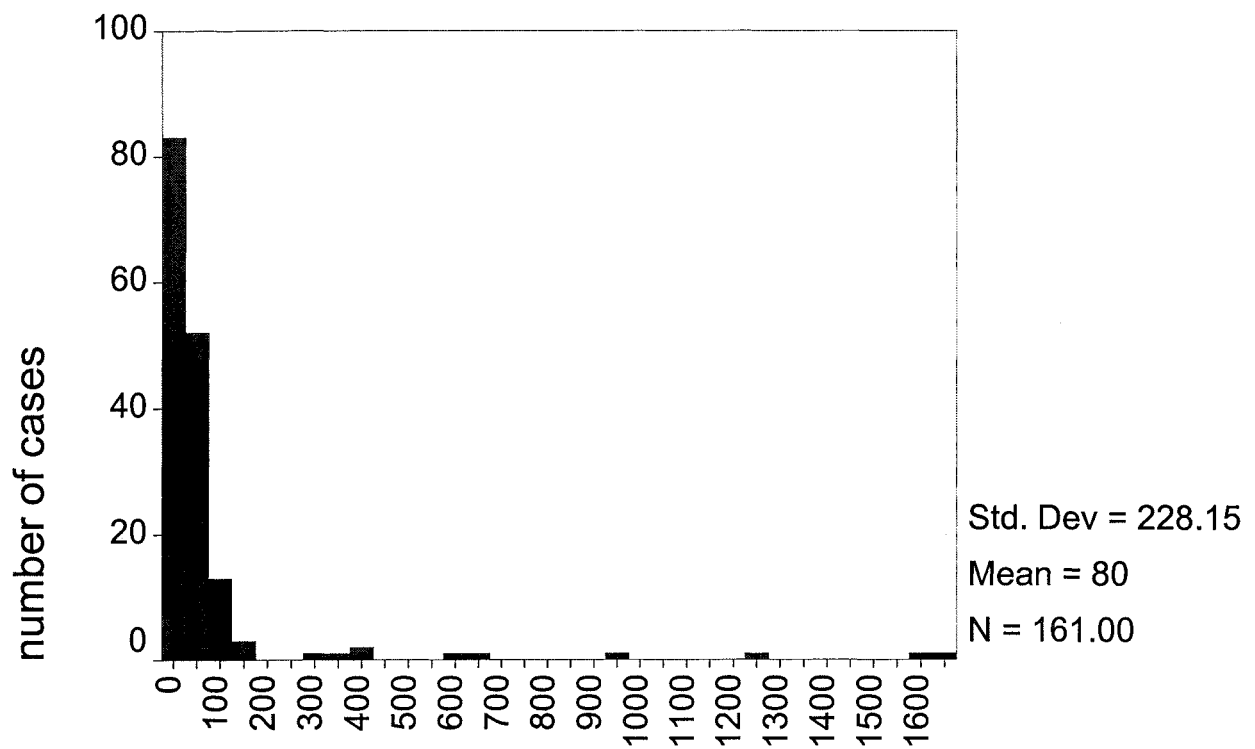


Histogram of contacts with GPs at home



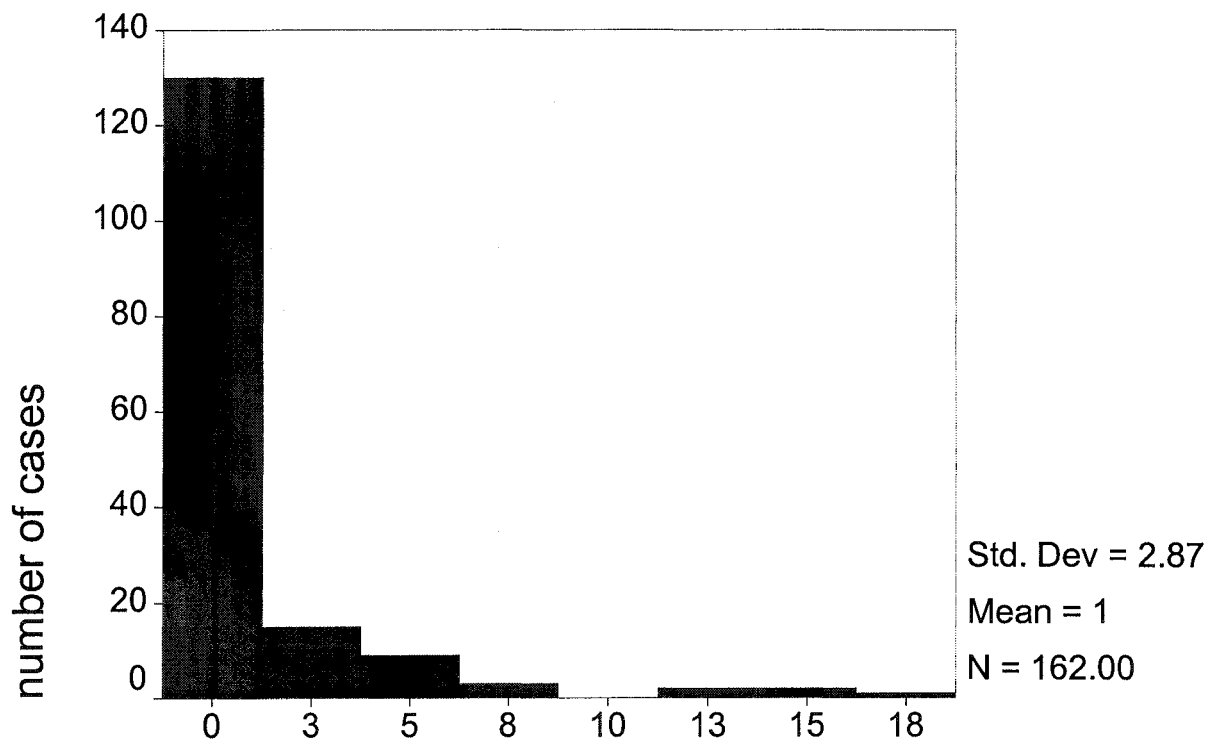
Contacts with GP at home

Histogram of contacts with all health workers



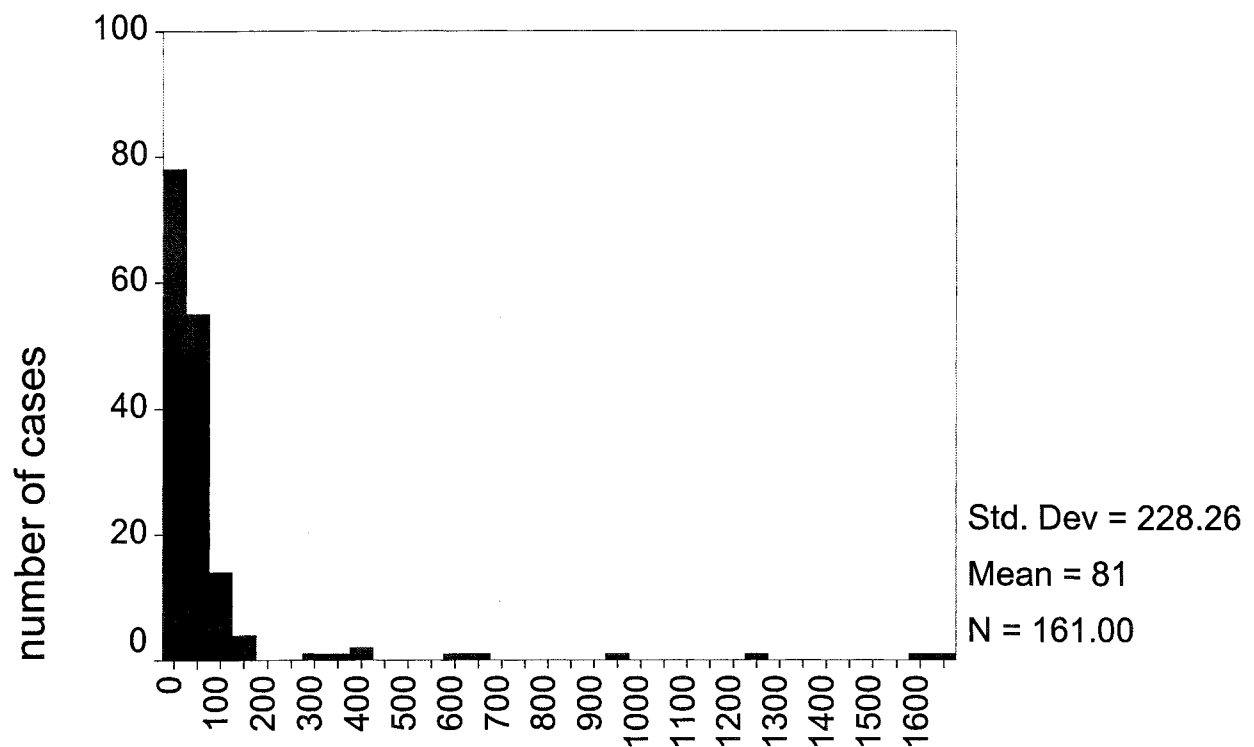
Contacts with all health workers

Histogram of contacts with all social services workers



Contacts with all social services workers

Histogram of contacts with all workers (health and social services)



Contacts with all workers (health & social services)

APPENDIX 11

CROSS-TABULATIONS OF *NONE VERSUS ONE OR MORE* CONTACTS FOR EACH INDIVIDUAL HEALTH AND SOCIAL SERVICE

Table 11.1 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with district nurses for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	44 (51%)	36 (48%)
One or more	43 (49%)	39 (52%)
Total	87 (100%)	75 (100%)

chi-square = 0.11(1DF) p = 0.74

Table 11.2 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with auxiliary nurses for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	69 (79%)	54 (72%)
One or more	18 (21%)	21 (28%)
Total	87 (100%)	75 (100%)

chi-square = 1.18 (1DF) p = 0.28

Table 11.3 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with out-patient physiotherapists for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	80 (92%)	64 (85%)
One or more	7 (8%)	11 (15%)
Total	87 (100%)	75 (100%)

chi-square = 1.79 (1DF) p = 0.18

Table 11.4 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with consultants for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	41 (47%)	31 (41%)
One or more	46 (53%)	44 (59%)
Total	87 (100%)	75 (100%)

chi-square = 0.55 (1DF) p = 0.46

Table 11.5 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with social services occupational therapists for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	79 (91%)	68 (91%)
One or more	8 (9%)	7 (9%)
Total	87 (100%)	75 (100%)

chi-square = 0.00 (1DF) p = 0.97

Table 11.6 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with social workers for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	68 (78%)	60 (80%)
One or more	19 (22%)	15 (20%)
Total	87 (100%)	75 (100%)

chi-square = 0.08 (1DF) p = 0.77

Table 11.7 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with domiciliary chiropodists for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	72 (83%)	67 (89%)
One or more	15 (17%)	8 (11%)
Total	87 (100%)	75 (100%)

chi-square = 1.43 (1DF) p = 0.23

Table 11.8 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with clinic chiropodists for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	75 (86%)	62 (83%)
One or more	12 (14%)	13 (17%)
Total	87 (100%)	75 (100%)

chi-square = 0.39 (1DF) p = 0.53

Table 11.9 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with domiciliary speech therapists for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	81 (93%)	72 (96%)
One or more	6 (7%)	3 (4%)
Total	87 (100%)	75 (100%)

chi-square = 0.64 (1DF) Fisher's exact p = 0.33

50% of cells with expected frequency < 5.

Table 11.10 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with GPs in the surgery for sample 1 (n= 161)

Contacts	Experimental group	Control group
None	52 (60%)	47 (63.5%)
One or more	35 (40%)	27 (36.5%)
Total	87 (100%)	74 (100%)

chi-square = 0.24 (1DF) p = 0.63

Table 11.11 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with GPs at home for sample 1 (n= 161)

Contacts	Experimental group	Control group
None	15 (17%)	12 (16%)
One or more	72 (83%)	62 (84%)
Total	87 (100%)	74 (100%)

chi-square = 0.03 (1DF) p = 0.86

Table 11.12 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with day hospitals for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	83 (95%)	70 (93%)
One or more	4 (5%)	5 (7%)
Total	()	75 (100%)

chi-square = 0.33 (1DF) Fisher's exact p = 0.41

50% of cells with expected frequency < 5.

APPENDIX 12

CROSS-TABULATIONS OF

***NONE* VERSUS *ONE OR MORE* CONTACTS**

FOR CUMULATED

HEALTH AND SOCIAL SERVICE CONTACTS

Table 12.1 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with all health workers for sample 1 (n= 161)

Contacts	Experimental group	Control group
None	1 (1%)	1 (1%)
One or more	86 (99%)	73 (99%)
Total	87 (100%)	74 (100%)

chi-square = 0.01(1DF) Fisher's exact p = 0.71

50% of cells with expected frequency < 5.

Table 12.2 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with all social services workers for sample 1 (n= 162)

Contacts	Experimental group	Control group
None	61 (70%)	55 (73%)
One or more	26 (30%)	20 (27%)
Total	87 (100%)	75 (100%)

chi-square = 0.21(1DF) p = 0.65

Table 12.3 Cross-tabulation by experimental and control group of number of contacts (none versus one or more) with all health and social services workers for sample 1 (n= 161)

Contacts	Experimental group	Control group
None	1 (1%)	1 (1%)
One or more	86 (99%)	73 (99%)
Total	87 (100%)	74 (100%)

chi-square = 0.01(1DF) Fisher's exact p = 0.71

50% of cells with expected frequency < 5.

APPENDIX 13

Dawson P and Heyman B (1997) Evaluating community health services:
conflict and controversy. *Health & Social Care in the Community*,
5, 255-260.

Evaluating community health services: conflict and controversy

Pam Dawson^{1,*} (MCSP) and Bob Heyman² (PhD)

¹Division of Physiotherapy and Applied Life Sciences, Faculty of Health, Social Work and Education, University of Northumbria at Newcastle, ²Division of Behavioural and Contextual Studies, Faculty of Health, Social Work and Education, University of Northumbria at Newcastle

Correspondence

Pam Dawson
Senior Lecturer
Division of Physiotherapy and
Applied Life Sciences
Faculty of Health, Social Work
and Education
University of Northumbria
at Newcastle
Coach Lane Campus
Newcastle upon Tyne
NE7 7XA
UK

Abstract

The best way to evaluate community health services remains the subject of much argument and debate. This paper explores difficulties encountered in the management of a randomized controlled trial of physiotherapy in a primary health care setting, and discusses conflicts which arose when carrying out a time limited commissioned evaluation of a carer support scheme. Although randomized controlled trials are still regarded as the gold standard in medical research, they can be difficult to coordinate, and often cannot be applied when patient problems are chronic or incurable and require multidisciplinary intervention. There are many cultural and organizational barriers that have to be overcome for evaluation to be successful and meaningful. If these barriers are underestimated or ignored, the quality of evaluation is compromised.

Keywords: carer support scheme, community physiotherapy, conflicts, ethics committees, evaluation, randomized controlled trial

Accepted for publication: 26 July 1996

Introduction

The need for good quality evaluation of health services has never been more apparent (Culyer 1994) and purchasers are increasingly funding evaluation research. However, it is easy to underestimate the extent to which organizational and cultural barriers limit the effectiveness of research based evaluation, particularly in areas where the standard model of clinical trials of precisely defined interventions cannot be applied. This paper will examine the role of evaluation research in the development of evidence based community health care practice, taking into account the organizational context in which community health care evaluations take place.

The NHS and Community Care Act (Department of Health 1990) attempted to create a 'market' for health and social care services and separated purchasers from providers of such care. Purchasers are expected to ensure value for money, and providers are expected to

compete in order to obtain contracts. It is not surprising that tensions have arisen in the purchaser/provider relationship, with purchasers appearing happier with the contracting process than providers (Appleby *et al.* 1994).

The randomized controlled trial (RCT) provides a means of evaluating specific medical interventions, and there have been calls for more RCTs (Pollock *et al.* 1993). However, late twentieth century western health systems have to deal mainly with problems that are long-term, involve conditions that cannot be cured, and require multidisciplinary interventions. Such problems have been described as 'wicked', a term first coined by Rittel & Weber (1974) and applied to health by Kingsley & Douglas (1991). Those who try to manage wicked problems have to confront moral dilemmas and to balance, for example, dependency against risk for vulnerable people, or the needs of people with health problems against those of their carers. It is not possible to define clear, consensual outcomes for the treatment of wicked problems. Pope & Mays (1993) have debated the relative merits of obtaining information about outcome and output of services through RCTs as against using ethnographic, observational methods to learn about processes

*PD was formerly Superintendent Physiotherapist at Newcastle Domiciliary Physiotherapy Service, Newcastle upon Tyne City Health Trust.

of service delivery. They make the point, which we will return to later, that methodological pluralism is required in health services research. User perspectives can provide an important component of community service evaluation, particularly where desirable outcomes cannot be defined easily (Heyman 1995) or when holistic or complementary therapies do not conform to the constraints of the RCT (Knipschild 1993).

Organizational procedures for implementing medically managed RCTs for specific interventions, e.g. drug trials, are well-established in the National Health Service. Randomized controlled trials are widely regarded as the gold standard in medical research and are argued to be the best way to gather evidence to underpin rehabilitation practice (Pollock *et al.* 1993, Wade 1995). However, the RCT does have limitations. The only real conclusion it is possible to make when rejecting the null hypothesis in a clinical trial is that the interventions being compared differ on the chosen outcome. Even theories which have been tested and verified several times can only be termed corroborated, not true in the absolute sense (Senn 1991) if one adopts a Popperian position. Neither random assignment nor controls are a panacea for all threats to reliability and validity (Cook & Campbell 1979, Senn 1991). Assumptions about the objectivity of RCTs are made by many researchers, who fail to acknowledge that even with rigorous procedures, there will often be interactions between treatment and patient variables. Patients are unique individuals, who respond to treatment in different ways (Knipschild 1993) and may well have preferences about how they should be treated (Brewin & Bradley 1989), which will influence their motivation and perhaps make them behave atypically. Validity is thus threatened when trials of participative treatments are interpreted as though they were drug trials, without considering the effects of psychological or social processes.

It can be much harder to evaluate services if the evaluation is not medically managed, and involves non-specific, multidisciplinary interventions, as illustrated by the two case studies outlined below. We discuss, firstly, a large scale RCT of domiciliary physiotherapy, and, secondly, a small scale evaluation of a support scheme for carers of terminally ill patients. The discussions will concentrate on organizational, ethical and cultural problems encountered while carrying out the research, rather than on the research results.

Evaluation of a new domiciliary physiotherapy service

An RCT of community-based domiciliary physiotherapy was undertaken in Newcastle upon Tyne between

1989 and 1992, supported by a £300 000 grant from the Sainsbury Family Trust Fund. Our discussion of the processes involved in the trial will focus on the following points. Firstly, problems can arise when control of research is shared between medical and non-medical professionals. Secondly, there are contradictions between the evaluation of services and their provision in conditions of scarcity. Thirdly, problems with sample recruitment and attrition can weaken the interpretation of results derived from RCTs, particularly where the interventions are complex, variable, long-term and social in nature. Fourthly, there are issues concerning the generalizability of demonstration projects, and the take-up of inconclusive findings of trials of complex interventions by purchasers.

The methodology of the RCT, in brief, was as follows. Two randomly allocated groups of clients were compared. One group received a new domiciliary physiotherapy service (experimental group), and the other received the best existing usual care (control group). The trial was set in the community, and criteria for referral were that the client had difficulty travelling to hospital, or had problems linked to the home environment, or that the carer required support. The RCT design was chosen because of its status as the gold standard in medical research, and as the design most likely to yield valid and reliable results. A pragmatic model (Schwartz *et al.* 1980) was adopted, with interventions optimized to meet the needs of individuals. Outcome measures included the Barthel Index (Collin *et al.* 1988) as a measure of functional ability, the Nottingham Health Profile (Hunt *et al.* 1986) as a measure of health status and clients' use of other services. The evaluation (which pre-dated the 1990 NHS reforms) was planned and implemented by the physiotherapy service, in order to meet the demands of the District Health Authority for valid data on service effectiveness.

It was intended to recruit a large sample (800 subjects) from all general practitioners (GPs) within the Health Authority boundary, in order to increase the power of statistical tests and maximize external validity (Altman 1991). From referral rates in an earlier pilot study it was estimated that recruitment would take approximately 6 months. At an early stage in the development of the trial methodology, it was proposed that some GP practices (chosen at random) would have access to the experimental service and others would not. This was, however, rejected by the Local Medical Committee (LMC), in favour of randomizing individual clients. The LMC thought it would be unfair to GPs who did not have access to domiciliary physiotherapy and who would therefore have to recruit clients solely for control purposes. Initially, it

was proposed that clients should be allocated to an intervention using the randomized consent design (Zelen 1979), where clients are not required to consent to participation in the trial, provided their treatment is as it would be under normal circumstances. Suitable subjects would be randomized into either the experimental or control group, and then the GP would seek only the consent of those receiving the new or experimental service. A fieldworker would then seek consent from both groups for data collection and interviews. The randomized consent design was rejected by the local medical ethics committee, which insisted that GPs should both recruit patients and seek their informed consent prior to randomization. Although many referrals in the pilot study had come from other primary health care team members, e.g. district nurses, the ethics committee would not allow anyone other than the GP to recruit subjects for the trial. GPs were given specific guidelines on patients suitable for the trial, but only recruited 245 subjects over a 12-month period (31% of the total required, in double the estimated time).

The reasons for the poor recruitment rate were varied. Some GPs claimed that the withholding of domiciliary physiotherapy from the control group would deprive patients of clinical benefit. However, there had never been a domiciliary physiotherapy service in Newcastle, and claims about the value of such a service were based on anecdotes, speculation, and precedents derived from other health districts, where services were being developed without evaluation. Other GPs objected to the RCT on the grounds that, as doctors, they should be able to freely access any service they felt would benefit their patients. It is possible that GPs felt unwilling to admit to patients that they were unsure of the best treatment (Taylor *et al.* 1984).

The problems discussed above are not unique to this trial of domiciliary physiotherapy. A paper published in the *British Medical Journal* (Tognoni *et al.* 1991) described the difficulties experienced by a group of Italian researchers attempting to conduct an RCT of the treatment of hypertension in general practice. They found a large discrepancy between the number of doctors who agreed to participate and the number who started recruiting, leading them to question the attitude of Italian GPs towards controlled research. Following the publication of the Tognoni paper, two letters were published in the *British Medical Journal* reporting similar experiences. Peto & Coulter (1991) wrote to the editor about their study of outcomes of treatment for menorrhagia in Oxford, in which they had to extend their recruitment phase because of lower than anticipated recruitment of patients by GPs. Two months later, Jonker & Sumajow (1992) reported on

their surveillance study of reflux oesophagitis in The Netherlands, in which, after a year, many GPs who had promised to cooperate had referred no patients. Greenberg (1991) congratulated Tognoni *et al.* for raising awareness of a problem that is usually glossed over in reports of trials in general practice.

Reasons for GPs' reluctance to enter patients into trials are discussed by Taylor (1992). She surveyed general physicians involved in a multicentred clinical trial in the USA and Canada and found that poor recruitment of patients was linked more to the social process of the RCT than to any inherent resistance or reluctance to support research. Although general physicians publicly argued that experiments were ethically wrong, or that trials were too time consuming, Taylor found that there were conflicting professional roles. American and Canadian general physicians (and presumably British GPs) normally get their rewards and social status from their individual doctor-patient relationship. They are supposed to reduce uncertainty for the patient, apply their knowledge, skills and experience to individual patient problems and then receive personal appreciation from patients and families when there is a successful outcome. Physicians surveyed in this RCT of treatment of eye cancer felt uncomfortable about random allocation taking over their decision making role, and they disliked admitting to patients that they didn't know which was the best treatment for them. They were uncertain about whether they could remain motivated to carry out administrative tasks when research was not perceived as high status work in general practice. Many physicians were also worried about shifting their allegiance from the present patient to future patients who would stand to benefit from the results of the RCT. The GPs involved in the trial of domiciliary physiotherapy must also have faced the dilemma of conflicting professional roles. However, because patients in the trial would be likely to benefit from the future service if the RCT were successful, the issue of asking patients to participate in a trial which would not benefit them directly did not really arise.

In the trial of domiciliary physiotherapy, the mechanisms for obtaining informed consent also caused problems. When research fieldworkers visited patients who had been recruited to the trial, it became apparent that, despite agreed protocols, many different explanations had been given by individual GPs. Some control group patients had false expectations that they would receive domiciliary physiotherapy. Although it is possible that GPs were deliberately sabotaging the trial, it is more likely that, because of their lack of research training, they were unaware of the implications of deviations from the research protocol (Jonker & Sumajow 1992).

Using research fieldworkers to obtain consent may well have prevented the problems caused by GPs failing to follow the agreed protocol. Subsequent patient dissatisfaction may have had some effect on sample attrition, which although higher in the control group (38%) than in the experimental group (29%), was not significantly different (chi-square = 2.34, $P = 0.13$). Although patients who refused to be interviewed formed only a small proportion of total dropouts, the difference between the two groups in refusal rates was highly significant. In the experimental group there were two refusals (2% of total patients recruited) compared with 13 refusals (11% of total patients recruited) in the control group (chi-square = 8.95, $P = 0.003$). In both the experimental and control groups, dropouts from the trial scored significantly worse on the Barthel Index and the social isolation item of the Nottingham Health Profile, suggesting that those subjects who had the most potential for measurable improvement on the scales were lost from the trial, thus affecting the interpretation of the results.

Some GPs were blatantly honest at the outset, saying that they supported the trial in principle, but were unlikely to recruit subjects due to the extra work involved in obtaining consent and collecting data. Extra workload is a predictable disincentive to GP involvement in trials (MacIntyre 1991). A financial incentive such as that given in many drug trials can compensate for extra workload (Waldron & Cookson 1993), but there is no evidence that paying GPs would have improved recruitment to the trial.

The findings of the domiciliary physiotherapy trial were inconclusive, showing no significant differences between the experimental and control groups. Exploratory analysis with sub-groups has suggested, however, that those clients who had received either day hospital or respite care used significantly less of these services if they were in the experimental group (Dawson 1995).

The failure to reject the null hypothesis may have been due to the smaller than intended overall sample size, the masking of real effects by differential sample attrition, or lack of sensitivity of the outcome measures. Despite these non-significant results, the study still had a marked impact on policy. The strength of feeling among GPs who didn't want their patients to be randomized into the control group indicated that physiotherapy was seen as having a necessary and positive role in the community. Since there was no evidence that experimental patients were in any way disadvantaged, a decision was made to continue the domiciliary physiotherapy service, despite the inconclusive evaluation findings. It was soon confirmed that many GPs had withheld potential referrals to the trial,

as their referral rates to the continued service immediately doubled (Dawson 1993). The domiciliary physiotherapy service has now regained its freedom to receive referrals from other health and social services colleagues.

The results of the trial may now be included in a national meta-analysis, to enhance the likelihood of discovering reliable trends across multiple research projects.

Evaluation of a new carer support scheme

This pilot scheme provided intensive support for carers of patients who were not suffering from cancer and were expected to live for less than a year. A district health commission had initially funded the scheme for one year (1994/95) and required the evaluation in order to decide whether to provide further funding.

Our discussion of the processes involved in the evaluation will focus on the issues which can arise when evaluation is tied to the one year purchasing cycle of health commissions, and the problems of evaluating innovative schemes targeted at vulnerable client groups.

As time and the research budget (£1000) were limited, the main evaluation tool used was a questionnaire given to caring relatives, to assess their perceptions of their support needs and the extent to which these were met by existing services.

An RCT was ruled out because there were strong ethical objections, from the voluntary agency funding the scheme, to subjecting carers of a dying relative to randomization. Additionally, there were problems in recruiting carers for what was a new service. Therefore a supply of 'subjects' for randomization was not available. Instead, an attempt was made to recruit a comparison group of carers who were receiving conventional support, e.g. district nursing and social work, from a neighbouring area. It was intended to recruit 30 carers into each group in order to permit statistical comparisons.

The local medical ethics committee in the trial district approved the proposal, but there was a 4-month delay in obtaining approval in the comparison district, and it was not possible to obtain data from this district before the funding deadline.

In the study period (May-November), only eight carers used the scheme, far fewer than had been anticipated. Recruitment was slow, firstly, because of the time required to publicize the scheme; secondly, because carers tended to stay with the scheme for several months, tying up its limited resources; and thirdly, because of the need for formal identification that someone was near to death. Some GPs refused to

enter carers into the scheme as they felt there were ethical problems in divulging a terminal diagnosis. Other professionals were also put off by having to certify that the relative being cared for had less than 1 year to live.

By insisting that the agency accepted only those who were terminally ill, the commission was attempting to ensure that they only funded 'health' and not 'social' care. However arbitrary this distinction may sometimes be, it is a fact of current organizational life in health and social services that one type of organization will be reluctant to fund a service which may overlap with the remit of the other. The action research format of the evaluation, which involved regular meetings between the researcher, the agency and the commissioning manager, made it fairly easy to renegotiate the terms of entry to the scheme when problems arose. Eventually the requirement, to certify that the relative being cared for had less than 1 year to live, was relaxed.

Of the eight carers who received intensive support, five returned questionnaires. These carers were very positive and rated the scheme more favourably than conventional services. However, with such small numbers, and in the absence of a comparison group, no statistical conclusions could be drawn. The evaluation of the scheme could only recommend that it should continue for another year for further data collection. This recommendation was accepted by the health commission.

A number of lessons can be drawn from this case study. Firstly, it is difficult to undertake RCTs with small-scale, innovative health care interventions, particularly in sensitive areas. Secondly, short-term funding cycles are incompatible with the time-scales required for ethical approval and data collection. Thirdly, the incidental 'action research' element of evaluations (in this case modifying the terms of reference of the carer scheme in order to improve recruitment) may be as useful as formal data collection and analysis.

Conclusions

The two case studies are at opposite ends of the spectrum, in terms of scale and methodology. However, both were problematic because of tensions between the requirements of ethical committees, health authorities, medical practitioners, clients and researchers. There is a long standing cultural divide between researchers, practitioners and managers (Roland 1995) and the difficulties illustrated by the case studies are, in our experience, endemic to non-medical health service evaluation. Systematic, replicable evaluations of complex interventions require the cooperation of a number of parties with different agendas, and may be more difficult to achieve than has been suggested by recent policy papers (Culyer 1994). What may be methodologically desirable

and ethically acceptable may not be politically possible because ethical committees or gatekeeper organizations do not allow it. Organizational barriers need to be addressed, particularly with respect to ethics committees. Problems with multicentre ethical approval are widespread in the UK (Garfield 1995, Middle *et al.* 1995, While 1995). A recent paper by Alberti (1995) calling for nationally coordinated ethics committees with common application forms is to be welcomed, and may pave the way for essential multicentre research. In order to foster community services evaluation, multicentre research is needed to provide controls for local initiatives. We would also recommend that researchers in primary health care consider using fieldworkers or other professionals, as well as GPs, to recruit patients to trials.

Where appropriate, client perspectives can be used to inform and sharpen an RCT design. They may also be used as meaningful outcomes in their own right. The client's own perspective may be the most valid source of information on service value, particularly when desired outcomes are variable and difficult to define. In the community context, where the focus of modern care is at the level of the individual, the process as well as the outcome of services are equally important. A more participative approach to research can have advantages in terms of learning quickly, from experience, about the process of service implementation.

Single experiments that yield non-significant results should not necessarily be ignored. Decisions often have to be based on imperfect knowledge, especially in applied research. It must be remembered that both experimental and non-experimental research, using either quantitative or qualitative data, can be flawed. No one method is inherently better than the other. All that can be said is that one may be more suited to a particular research problem. It is our view that a broad pragmatic approach to methodology is required if research is to be relevant to holistic community-based practice.

Acknowledgements

The Newcastle domiciliary physiotherapy trial was funded by the Sainsbury Family Trust Fund. The following project advisory group members provided valuable scientific and practical guidance: Prof. John Bond, Dr Barbara Gregson, Mrs Sylvia Hogarth, Dr Judith Hooper, Dr David Parkin, Dr Pauline Pearson and Prof. Rowena Plant.

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